



# **A conceptual framework for breast nurses' practice in rural settings: a pragmatic mixed methods study**

By

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Doctor of Philosophy

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# Abstract

Breast cancer typically causes significant disease burden for women, often compounded by complex and fragmented cancer care. Breast nursing roles support women by providing supportive care and care coordination. However, most of what we know about breast nursing is from urban settings. Major gaps in knowledge exist around how breast nurses effectively undertake real world practice in rural areas.

This thesis addressed an important gap in the literature by comprehensively describing breast nursing practices in naturalistic rural contexts. The study builds on previous breast nursing research by emphasising a focus on rural context, factors influencing nursing practices, and considering whether clients' needs are met (i.e. effectiveness). The research process followed a sequential, explanatory mixed method design to answer the question: *What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?* Three breast nursing services in varying rural sites are described, and summarised to compare with previous reports of breast nursing. Quantitative data over a one-year period provided descriptions of overall rural breast nursing practices, and consultations with women. During the same time period, clients' supportive care outcomes were gathered through longitudinal surveys of unmet needs. These quantitative results informed semi-structured interviews with rural breast nurses about what they do, and what influences their practices. Together, the quantitative and qualitative findings informed the conceptual framework developed within this thesis.

The conceptual framework for rural breast nurse practice incorporates the key interacting features that shape rural breast nursing practices. Client's needs are determined by individual characteristics, circumstances, and journeys which, in turn, influence nursing practices. Nurses' personal and professional features, including their experiences and relationships, individualise rural breast nursing

practices. Physical and socio-cultural contextual features within organisations and wider healthcare systems create the parameters that define what is possible within each site. Significantly, features related to clients', nurses', and healthcare providers' availability and accessibility are important to the effectiveness of rural nursing services.

This thesis provides unique insight because it considers the context of real world practice and acknowledges the need for diversity in nursing practices to reflect individual settings. It recognises that there are a multitude of influences on nursing practices, and specifically highlights nurse and contextual features, which are generally not acknowledged in the breast nursing literature. Additionally it provides a comprehensive description of rural breast nursing practice whilst acknowledging its place within a system of cancer care.

The study outcomes inform the establishment and improvement of rural breast nurse services by identifying the influences of clientele, nurse, and contextual features that should be considered when planning services. A conscious focus on the availability and accessibility of all elements will maximise the quality of interventions and outcomes. Additionally, the outcomes inform the recruitment and education of breast nurses, particularly those in rural areas. Educational programs should specifically aim to develop their candidates' clinical confidence for effective advanced nursing practice. Clinical confidence and relevant experience should be essential criteria for positions. Future research should build knowledge around the need for advanced nurses' educational preparation, skill level, and diplomacy (e.g. what is it and how to teach it) and educational institutions can incorporate this knowledge into curriculums. The significance of the variability in nursing practice identified in this study would also benefit from further research.

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Firstly, I must gratefully acknowledge the nurses and women who participated in this study. The nurses in particular gave generously of their time and insights. It is through them that I was welcomed to explore their world. I thank them for trusting me. Moreover, the women who agreed to participate did so during a challenging time, with no benefit to themselves.

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# **Chapter One: Introduction – Why is Rural Breast Nurse Care Worthy of Investigation?**

People of the developed world are living longer due in part to improved hygiene, nutrition, safety measures, and medicines. Major public health concerns have changed from treating infections and injuries to treating and managing chronic diseases. Cancer is one such disease which has increased in prominence, and is the leading cause of death worldwide (WHO 2003).

The importance of providing supportive care for people with cancer has gained recognition. This care extends beyond treating the cancer, and instead involves supporting the client's broader experience with cancer and minimising its negative impact on his/her life. Most notably, the supportive care of women with breast cancer has received significant attention. Additionally, rural people diagnosed with cancer are understood to have added challenges arising from the effects of cancer and its treatment on their lives. Cancer services in rural areas tend to be undersupplied, leading to additional difficulties for rural people diagnosed with cancer. This study focuses on the support services of rural women with breast cancer in order to improve both health services and outcomes for women.

This chapter details the importance of and rationale for this study. It demonstrates there is little research to guide effective and sustainable rural breast nursing services to improve women's experiences with breast cancer and their psychosocial outcomes. It provides an introduction to this research study, along with an outline of the thesis chapters.



## **1.1. Significance of Rural Supportive Breast Cancer Care**

Of all cancers, breast cancer has a substantial profile arising from its significant burden of disease and women's negative experiences with its diagnosis, treatment, and sequelae. Unfortunately, the care of women with breast cancer is often fragmented due to treatment complexity and poor communication between multiple providers. To improve women's outcomes and experiences, supportive cancer care is provided by designated nurses. Deficiencies in rural cancer services mean this sort of supportive breast cancer care could be especially beneficial for clients residing in rural areas.

### **1.1.1. Breast Cancer – Disease Burden, Women's Experiences, and High Profile**

Breast cancer causes significant burden of disease through mortality and morbidity. Indeed, breast cancer is the second most common cancer worldwide (WHO 2003). In Australia, breast cancer causes the largest number of 'lost years' through death of all diseases among females (AIHW 2010). Improved breast cancer detection and treatment have resulted in improved survival. Specifically, there has been a marked improvement in 5-year relative survival from breast cancer bringing it to over 88% (AIHW 2010). Nonetheless, breast cancer was expected to cause the greatest disability adjusted life years for Australian females in 2010 (AIHW 2010). Breast cancer survival often comes at a cost to quality of life, as women suffer both short and sometimes long-term repercussions from treatment. Furthermore, women's difficult experiences can contribute to poor psychosocial outcomes.

Physical, psychosocial, and practical difficulties for patients associated with cancer diagnosis and treatments are well documented in the literature. Breast cancer diagnosis and treatment can affect multiple aspects of women's lives e.g. physical, psychological, economic and social. Common sequelae for people with cancer and women with breast cancer in particular are:

- depression (Alfano & Rowland, 2006; Deshields et al., 2006; Maguire et al., 1978; Montazeri, 2008),
- anxiety (Alfano & Rowland, 2006; Deshields, et al., 2006; Maguire, et al., 1978; Montazeri, 2008),
- distress (Alfano & Rowland, 2006; Montazeri, 2008; White & Mcleod, 2002),(Zabora et al., 2001)<sup>1</sup>,
- exaggerated fear of disease recurrence and/or death (Chantler et al., 2005) (Alfano & Rowland, 2006; Connell et al., 2006), and
- poor body image and sexual functioning (Montazeri, 2008).

Common symptoms during and after treatment include fatigue (Montazeri, 2008; Wagner & Cella, 2004), pain, arm morbidity and postmenopausal symptoms (Montazeri, 2008). Furthermore, women report high unmet psychosocial needs (Girgis et al., 2000; Thewes et al., 2004a), and unmet information needs (Girgis, et al., 2000). Considerable adjustment is required, and many women face difficulties in this adjustment (Beatty et al., 2008; Kissane et al., 1998; McGrath et al., 1999).

Women with breast cancer are recognised as a patient group who report problems and high levels of need across the illness trajectory (Baker et al., 2005; Lindop & Cannon, 2001). These women are high utilisers of healthcare services (Carlson et al., 2004) and repeatedly report their cancer journey to be fragmented, uncoordinated, and confusing which certainly impacts their experiences (NBCC Commonwealth of Australia, 2001; 1999).

People living in rural areas with cancer are identified as having extra burdens related to their rurality. For instance, they confront longer travel distances for treatment and specialist services, and less access to mental health services (Bettencourt et al., 2007). Specifically, they face challenges in ‘becoming aware of

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<sup>1</sup> One study found the overall prevalence of psychological distress among breast cancer patients to be 33% (Zabora, et al., 2001).

and/or gaining access to healthcare information, support and services' (Gray et al., 2004). An Australian study found 89% of rural women with breast cancer reported problems specific to being rural (Davis et al., 2003). Rural issues include concerns about the family's ability to cope during absences (McGrath, et al., 1999), travel (Davis, et al., 2003; Hegney et al., 2005), financial worries (Fitch et al., 2003; McGrath, et al., 1999), and difficulty organising financial assistance (Davis, et al., 2003; McGrath & Segueria, 1999). One study revealed Australian rural women with breast cancer were two and a half times more likely than urban women to report some need for help (Girgis, et al., 2000).

Due in part to breast cancer's prominence and significant disease burden, it holds a substantial profile within many western countries including Australia, with interest from consumers, health professionals, and governments. A strong consumer lobby presence helps drive interest and support for breast cancer issues in Australia and other western countries (BCNA, 2011). Consumer movements have assisted in driving a patient-centred care agenda, including patient's involvement in decision-making (Tritter & Calnan, 2002). Health professional's attention to breast cancer has come in the form of research, professional development, and advocacy.

There is also significant government attention on breast cancer, including clinical and public health. Cancer control is a National Health Priority Area for the Australian Government, with breast cancer one of the eight priority cancers (AIHW 2010; National Health Priority Action Council, 2006). Furthermore, several relevant and important clinical practice guidelines have been developed over the past 10+ years within Australia (NBOCC 2010; NBCC and NCCI 2003; NHMRC NBCC 1999) (iSource NBCC 2001). These guidelines were intended to provide evidence-based recommendations to guide cancer care (Turner et al., 2005). Breast cancer specific services and projects have also been instigated by the Australian Government (for example: Campbell et al., 2003; and Cancer Australia, 2011).

Overall, given breast cancer's significant burden of disease, women's experiences, and the public and political attention it receives, breast cancer care is important. So, what care is generally available to women diagnosed with breast cancer?

### **1.1.2. Breast Cancer Care - Complexity and Fragmentation**

In most western countries, cancer care is provided within complex healthcare systems. The Australian system is mixed with both public and private services, with a trend towards more private services (Cook, 2006). Cancer services are particularly complicated as they are provided across multiple sites with the involvement of various disciplines and the use of diverse treatment pathways. The complexity includes various levels of healthcare organisation (hospitals and doctors' surgeries, specialists and generalists, etc.) and systems (public and privately funded insurance and locations) (Griffiths, 2003). To complicate matters further, these care services and systems are interdependent (Productivity Commission, 2005). Additionally, treatment advances have increased complexity, which is particularly evident for breast cancer (Kaufman, 2004).

Breast cancer care typically involves mammography, ultrasound, surgery, radiotherapy and/or chemotherapy, and hormone treatment. From diagnosis to follow-up, women may receive care from a litany of health professionals such as: general practitioners, mammographers, surgeons, radiation and/or medical oncologists and sometimes physiotherapists, social workers, and reconstructive surgeons. Yet, care plans typically differ as they are recommended based on each individual cancer. Complex cancer care systems and diverse complicated pathways, coupled with poor communication and collaboration between the multiple providers involved, has led to patients experiencing fragmented breast cancer care (Chew & Weyden, 2002; Farber et al., 2002; Mann, 2005). Moreover, treatment advances and specialisation further complicate care. Yet, continuity of care is important to both providers and patients (Patient Navigation in Cancer Care Project, 2003).

In response to care fragmentation along with the aforementioned unmet needs and psychological morbidity of women, coordination roles have been introduced with an increased focus on supportive care.

### **1.1.3. Supportive Cancer Care and Nurses' Contributions**

Supportive care is an important part of cancer care, having the potential to improve patient experiences and outcomes (NBCC and NCCI 2003; NHMRC NBCC 1999) as well as reducing healthcare costs (Carlson & Bultz, 2004). Nurses' contribution to supportive care is both unique and complimentary to that of other health providers (Yates, 2004). Nurses regularly incorporate supportive care into their work in the ways they interact with clients. Specifically, nurses traditionally provide holistic person-centred care (Yates, 2004), educate patients (Oermann & Templin, 2000), and develop trust through empathic communication which makes them approachable to clients (Dunniece & Slevin, 2000).

The nursing workforce is extensive in size, while the cancer nurse workforce is also substantial (Yates, 2004). There are more than 11 million nurses providing care in various settings worldwide (Henke Yarbrow, 2003). Nursing groups make up over 50% of the Australian health workforce (Productivity Commission, 2005). Nurses are in an ideal position to influence breast cancer care despite challenges such as nursing shortages and limited resources (Barrett, 2004; Henke Yarbrow, 2003).

Nurses can play a key role in supportive cancer care. In particular, cancer nurses play a pivotal role in the healthcare system which positions them to coordinate services across various healthcare sectors (CNSA 2002; Yates, 2004). Nurses have contact with breast cancer clients in a range of settings, on wards (Mohan et al., 2005), in homes (Hughes et al., 2000), at nurse-led clinics (Cox & Wilson, 2003; Loftus & Weston, 2001), and in specialised nursing roles. However, ward nurses report a lack of time, training and knowledge to provide appropriate individualized care to their patients (Mohan, et al., 2005). Oncology nurses also perceive they do not have the time or training to provide the psychosocial care they believe patients

should receive (Watts et al., 2010). Therefore, as other nurses lack the time, training and skills to appropriately provide the supportive care clients require, designated supportive care roles have developed to address clients' unmet needs.

Designated supportive cancer care roles have developed internationally to attend to unmet needs whilst improving psychosocial outcomes and care coordination. These include for example cancer care nurses, professional and volunteer patient navigators (Farber, et al., 2002; Patient Navigation in Cancer Care Project, 2003; Shockney, 2010), and volunteer health visitors (Plews et al., 2005). These supportive cancer care services are provided in both community and tertiary settings (Farber, et al., 2002). Their patients report specialist nurses in cancer care are unique in their availability to clients and ability to liaise with clients and the wider health system (Tarrant et al., 2008).

Breast nurses (BNs), typically referred to as Specialist Breast Nurses or Breast Care Nurses, are one such designated supportive cancer care role<sup>2</sup>. These roles have demonstrated beneficial outcomes for women with breast cancer through a strong evidence base (NHMRC NBCC, 1999; Liebert et al., 2001), as discussed extensively in the next chapter (Chapter Two).

#### **1.1.4. Emergence of Breast Nursing**

Breast nurse roles have been established and expanded within Australia and internationally. A demonstrated need for the supportive care for women with breast cancer led to the role of the BN. Medical practitioners have contributed to the push for BNs in recognition of the beneficial role they play in supporting the work of surgeons and oncologists (Hordern, 2000). BN roles have undergone rapid development as cancer care has become more specialised, and the potential for RNs to provide supportive care has been demonstrated (NBCC and NCCI 2003).

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<sup>2</sup> Nurses who work with women with breast cancer are given many titles. The term 'breast nurse' has been

BN roles have been developing for over 20 years and have proliferated internationally, particularly in the United Kingdom, Australia, Scandinavia, and North America (Cruickshank et al., 2008) and more recently in Europe (Claassen, 2009; Eicher, 2009) and New Zealand (Haward et al., 2003). The role has evolved to take on many forms within various countries and numerous locations in healthcare systems. Established BNs primarily exist within comparatively well-resourced healthcare systems (Cruickshank, et al., 2008), though roles assisting breast cancer patients to navigate the healthcare system were recently described in Ethiopia (Dye et al., 2010).

The BN role originated in the United Kingdom (UK). BN positions have been a well-established component of best practice in the UK since the 1970s and are typically based in hospital settings. At the millennium, BNs held considerable credibility and their services were universally available across the country (Ambler et al., 1999). Tumour-specific clinical nurse specialists are common in the UK, many of which are provided by the Macmillan organisation. Mapping exercises and audits of the UK cancer clinical nurse specialist workforce show the breast cancer subspecialty to be the most common (with around 400 posts), accounting for one in five of all adult cancer nurses in England, though distribution is variable across cancer networks (Trevatt & Leary, 2010; Trevatt et al., 2008).

The emergence of BN and other supportive cancer care roles internationally have evolved independently while also influencing one another. The UK has played a lead role in the BNs emergence, with specialised Macmillan nurses now entrenched in public practice (Macmillan Cancer Support, 2010). In Scandinavia, emphasis on follow-up care is predominant (Koinberg et al., 2009; Koinberg et al., 2004; Kossler, 2006), whereas other parts of Europe have a diversity of BN forms attached to accredited breast units supporting women from diagnosis and beyond (Claassen, 2009; Eicher, 2009; Eicher, 2010). In North America and elsewhere supportive cancer care for women with breast cancer is often undertaken by generalist supportive roles which overlap with the aims of the BN (Pedersen & Hack, 2010;

Shockney, 2010; Wells et al., 2008). Australia has also contributed to the establishment, expansion, and knowledge of BN roles.

Within Australia, BNs are generally well established in metropolitan treatment centres and cancer clinics. Although the first Australian BN position was established in South Australia in 1979, the role did not gain prominence and attention until the 1990s, as marked by the first annual National Breast Care Nurses Conference in 1999. During this time, and since then, there has been a rapid, uncoordinated expansion of BN roles.

In 1999, the BN was first described in the Australian context at the same time as oncology nurses were recognising they lacked the time and skills to provide the emotional support that women with breast cancer required (White & Wilkes, 1999b; Wilkes, White, et al., 1999). In 2000, the National Breast Cancer Centre (NBCC) published the Specialist Breast Nurse (SBN) Demonstration Project to provide an evidenced-based model for Australian practice (SBN Project Team, 2000). This Project is described later in this chapter. Additional breast nursing practices described in Australia include a trial in a traditional metropolitan hospital setting, and recently in the Australian rural and remote context (Eley et al., 2007; Eley et al., 2008; Szwajcer et al., 2004).

#### **1.1.4.1. Disparities in Access**

Women's access to BNs in Australia has naturally increased as the role has become more popular and accepted. For instance, Queensland Australia had four BN positions in 2001 and 16 BNs six years later to service a population of over 4.5 million (Eley, et al., 2008). However, access is inconsistent for women across locations and insurance statuses, and varies at different points in the cancer journey.

Australian audits indicate an overall improved access to BNs for women with breast cancer. Namely, an audit of a population-based sample of Australian women with breast cancer was undertaken in 1997, and Australian and New Zealand surgeons



were asked in 2006 about their access to BNs within or outside their practices<sup>3</sup>.

Comparisons of the two studies indicates an increase in the percentage of women having access to a BN, from almost 50% in 1997 to over 80% in 2006 (Campbell et al., 2006; Marsh et al., 2010). However, the finer details of the audit results provide evidence of disparities in who has access, when BNs can be accessed, and how services are provided.

Some studies identify disparities in **who** has access to BNs in Australia, with rural women and those privately insured having less access (e.g. Marsh, et al., 2010). Rural surgical practices were significantly less likely to have access to a BN than either metropolitan or regional practices (Marsh, et al., 2010). Decreased BN access for private surgical practices was mainly explained by differences in public and private practices in metropolitan and regional areas, as rural practices did not have differences in access related to health insurance status, i.e. rural public and rural private practices had similar low levels of access to BNs (Marsh, et al., 2010). Yet, decreased access for private patients has been echoed elsewhere in the literature (Victorian Centre for Nursing Practice Research, 2001). On the other hand, an earlier study found no significant difference in access to BN care arising from geographical location (Campbell, et al., 2006). Yet, it was uncertain if respondents were clear on what a BN is/was (Campbell, et al., 2006).

There are also disparities in **when** women have access to BNs in Australia. There are points in the cancer journey when women commonly do not have access to BNs, namely adjuvant treatment and follow-up. Australian breast nursing is skewed to diagnosis and early treatment, and often excludes later treatment and/or follow-up. For example, while almost two-thirds of women who saw a BN had contact with her immediately after surgery, only about one quarter of women had contact with her 2 to 4 months following surgery (Campbell, et al., 2006). This gap in services has been

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<sup>3</sup> It should be noted that although surgeons reported access to BN services, it is unclear how much of that access was translated to women.

identified by both dedicated and non-dedicated BN roles, and is consistent with the recent audit of surgeon's access to BNs (Marsh, et al., 2010; Victorian Centre for Nursing Practice Research, 2001).

Finally, there are disparities in **how** women receive BN care in Australia. Most women seem to receive two or fewer consultations with a BN. Systemic BN care, meaning at least 3 consultations preoperatively, postoperatively, and at follow-up, appears to be rare. In 1997, only 11% of women who consulted a BN received systemic care (Campbell, et al., 2006). Public hospital attendance and receipt of systemic adjuvant therapy (i.e. treatment following surgery, such as chemotherapy) were positively associated with systemic BN care, whereas the type of surgery (i.e. breast conserving or mastectomy) or receipt of radiotherapy was not associated (Campbell, et al., 2006).

There are clearly discrepancies in access to BNs for women in Australia. The considerable variability in women's access to BNs affects the quality of care they receive (Livingston et al., 2000; Victorian Centre for Nursing Practice Research, 2001), as has also been found for men with prostate cancer accessing prostate cancer clinical nurse specialists (Ream et al., 2009)

#### **1.1.5. Rural Context**

Rural medical practice differs in context, content and process of care from urban practice (Smith & Hays, 2004). As rural health practice is distinct, rural health providers face similar issues related to rurality (Bourke et al., 2004). Not only may their clients and their needs differ, the conditions under which rural health providers work differs from their urban counterparts. For example, isolation, self-reliance, insider/outsider, and role diffusion are recurring themes for rural advanced practice nurses (Puskar et al., 1996; Smith & Hays, 2004). Additionally, rural health provider education, recruitment, and retention are common challenges impacting rural service provision (Chenoweth, 2004; Daniels et al., 2007; Mills et al.,

2010; Mills et al., 2005), with significant barriers to continuing education for rural service providers (Penz et al., 2007).

The rural health literature suggests rural health service design requires special consideration. It is important to consider structural factors when determining the best array and arrangement of rural nursing services (Dunkin, 2000). For instance, one study highlighted that co-location of nursing teams in rural settings improved communication of information (Woodhouse, 2009). A design framework built from available research has been proposed to optimise health care service effectiveness in rural areas (Mueller & MacKinney, 2006).

Context has increasingly been recognised as influencing rural health services (Ross, 2008). Specifically, rural context shapes rural nursing practice (Howie, 2008a, 2008b; Puskar, et al., 1996) and influences how people manage their own health issues (Winters et al., 2006). For example, healthcare and other public infrastructures “influence healthcare delivery systems and services in those regions” (Bushy, 2002, p.104). Subsequently, nurses’ care is often shaped to address the gaps in support left by existing services, and the resulting systemic issues for clients (Howell et al., 2008; Pedersen & Hack, 2010).

While rural nursing theory is in its infancy (Long & Weinert, 2010; McCoy, 2009; Scharff, 2010; Winters & Lee, 2010), studies highlight the importance of social capital and connectedness for rural nursing providers and their practice (Conger & Plager, 2008; Lauder et al., 2006). Comparisons made between rural nursing practice in Australia, Canada, and the USA highlight recurring themes, such as nurse role diffusion and care being achieved through partnerships (Bushy, 2002). Bushy (2002) also highlighted the importance of rural nurses’ familiarity with the formal and informal resources available to their clients and how to gain access.

Similarly, rural cancer care, and what is needed by patients, may differ from urban areas. Indeed, the context of practice is increasingly recognised as impacting client, provider, and service outcomes (McCormack et al., 2002). In Australia,

approximately one third of the population lives in regional and rural areas (AIHW 2004). Thus, a significant proportion of Australian women diagnosed with breast cancer reside in rural and remote communities.

Rural cancer care typically demonstrates substantial deficiencies which further burden the challenges inherent for rural individuals being diagnosed and treated for cancer. Therefore, rural supportive cancer care - working to improve continuity and coordination - may be even more beneficial and important to rurally based patients.

Defining rural and remote communities is challenging. There has been confusion and inconsistency in the use of the terms regional, rural and remote (Hugo, 2002). Their use is often an attempt to define two different conceptual elements: urban/rural and accessibility/remoteness (Hugo, 2002). Despite the lack of an international consensus to define rural, it is typically defined as fewer people distributed over greater distances (Howie, 2008b). For the purposes of this thesis, rural is defined as their common feature i.e. communities residing 'some distance' from major metropolitan centres (AIHW 2004).

Categorising rural areas and rural populations can also be challenging as they include great diversity (AIHW 2010). Importantly, rural contexts are heterogeneous in nature (Howie, 2008a). A complex diversity differentiates non-metropolitan Australia and generalisations are often unhelpful (Hugo, 2002). Nonetheless, it is important to understand demographic, social and economic trends in each area to ensure programs and policies are appropriate and efficacious (Hugo, 2002).

While the characteristics of Australia's rural communities are quite diverse, they share several common features (AIHW 2010). They commonly have socio-economic and health disadvantage as compared to their urban counterparts. Non-metropolitan Australia has higher proportions of low-income groups (Hugo, 2002) and lower education levels (Phillips, 2002). Also, rural areas have older demographic profiles which shape needs and demands for health services (Asthana et al., 2003; Hugo, 2002). Furthermore, rural Australians are not as healthy as their

city counterparts (AIHW 2010). Australians living within rural and remote areas are typically characterised by health disadvantage due to their locality, higher levels of illness and higher prevalence of mental health problems than those in major cities (AIHW 2010).

However, cancer services in rural areas do not reflect the challenges brought about by these common features. A recent mapping study identified deficiencies in cancer services in rural and regional Australia (Underhill et al., 2009). Similarly, other reports have also identified inadequate surgical and medical specialties, and critical gaps in allied health services and multidisciplinary care and psychosocial support in rural Australian cancer services (Begbie & Underhill, 2007; COSA 2006). Consequently, women with breast cancer from rural areas are less likely to receive adequate care (Haggstrom et al., 2005). Moreover, improvements are needed in rural cancer care coordination as rural services tend to be even more disconnected than urban areas (McConigley et al., 2010).

Furthermore, rural Australia has significant workforce shortages in mental health services (Productivity Commission, 2005), which may add to the difficulties of servicing the increased burden of rural people with cancer. Specifically, rural women with breast cancer have less access to mental health services (Bettencourt, et al., 2007). Thus, in the context of limited specialised mental health services, the provision of psychosocial interventions rests with medical and nursing professionals (Gray et al., 2002).

In the absence of robust rural cancer services, rural cancer nurses in particular play a major role in delivering services to rural and remote communities (CNSA 2002). Accordingly, in Australia “the definition of rural nursing has been widened to include nurses working outside of major metropolitan areas where patients have reduced access to health services” (Mills, et al., 2010, p.31). Indeed, much of rural supportive care falls to the nursing profession as a higher proportion of care in rural Australia is provided by nurses (AIHW 1998; Productivity Commission, 2005).

Given the complexity of cancer care and treatments combined with deficiencies in rural cancer and mental health services, rural clients may experience greater need for care coordination and supportive cancer care. Cancer nurse coordinators may be especially useful in improving care coordination in rural and regional areas (Drury & Inma, 2010; McConigley, et al., 2010). Indeed, the importance and value of BN positions for rural areas has been highlighted (Rogers-Clark, 2002). Yet, “because of differences in the distributions of their populations, rural and urban areas present quite different challenges for the optimal design of health services” (Asthana & Halliday, 2004, p.457).

However, a lack of research to inform effective and sustainable rural breast nurse (RBN) services has emerged as a problem holding back rural supportive cancer care development. Information which is available, namely nursing models and what is known about actual nursing practices is mostly urban based. This is discussed in the next section, and more extensively in the next chapter (Chapter Two).

## **1.2. Rationale for Investigating Rural Breast Nursing**

The need for this study arises from the scant evidence available to guide the development and improvement of RBN services. While few models are comprehensively described in the literature, an Australian SBN model of care is an important exception. However, this model does not appear suitable for rural nursing practices. Similarly, the scientific evidence about the structure of BN services primarily comes from urban best practice contexts. This evidence does not readily translate to diverse rural settings.

### **1.2.1. Few Models of Breast Nurse Practice**

Those planning and managing services require information about how BN roles are/can be structured. Thus, relevant evidence to guide the development of BN services can assist health service planners. While comprehensive descriptions of nursing practices are useful, often models of care provide the basis from which to

develop new services. A model of care provides the overarching design and/or structure within which policy makers, health service managers, and nurses go about the resourcing, organising, and implementing of an intervention (Davidson et al., 2006, p.49).

However, few models of BN care exist in the literature, and of those that do exist, there is lack of uniformity (Eicher et al., 2006). The literature contains few descriptions of models of care, and the clinical pathways BN services follow. Instead, descriptions and evaluations tend to have limited depth and/or breadth. Description of breast nursing practices with enough detail to be replicated has been provided on few occasions in the scientific literature (for example: Clacey et al., 1988; and Howell, et al., 2008). One important exception, which is particularly relevant to the Australian context and this thesis, is the NBCC SBN Demonstration Project which is discussed in this section (SBN Project Team 2000).

Detailed descriptions provide insights into how BNs structure their work, and can inform the development and improvement of effective services in different settings. For example, Clacey et al (1988) provided an early description of BN practice which was replicable. Although limited to describing a single nurse service, it details the content of three post-operative consultations, their timing in the cancer journey, and their approximate duration. Additionally, albeit a general cancer supportive care role, Howell et al (2008) provided a useful comprehensive description of the Interlink Community Cancer Nursing model of care, and how it operated in the Canadian home setting. Significantly, an individualised and holistic approach to care was described which was shaped to address clients supportive care needs and “gaps in support provided by existing services” (Howell, et al., 2008, p.1348).

The NBCC SBN Demonstration Project provided both a model of care and comprehensive detailed descriptions of the model in practice. This was a 12 month multicentre prospective study. It represents the most thoroughly detailed model of BN care in the academic literature, and includes the evidence base, multicentre implementation, women’s perceptions of the model in practice, and the SBN’s

detection and referral for psychological morbidity (Liebert & Furber, 2004; Liebert, et al., 2003; Liebert, et al., 2001; Parle et al., 2001). Moreover, a project report provides further detail of how the model of care was implemented by seven SBNs through four collaborating centres across Australia, including a rural site (SBN Project Team 2000)<sup>4</sup>. Importantly, this includes a useful clinical pathway (Liebert, et al., 2001).

The '5 in 12' clinical pathway utilised in the NBCC SBN Demonstration Project describes five consultations over a twelve-week period extending from diagnosis to follow-up. Each consultation included elements of information and support, and were staged to correspond with the common treatment trajectory: diagnosis (during or immediately after), pre-operatively, post-operatively, 1-6 weeks post-operatively (follow-up one), and 6-10 weeks post-operatively (follow-up two). The option for additional patient-initiated consultations is highlighted at each stage. The SBN's actions in introducing, checking, and discussing different elements of care and coping are listed in a useful one-page intervention protocol summary (Liebert, et al., 2003).

The NBCC SBN Demonstration Project is valuable for a number of reasons. Firstly, the model was distilled from the highest level of research. Secondly, it was

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<sup>4</sup> Four collaborating centres engaged SBNs to apply the intervention protocol at a range of Australian sites: Royal Adelaide Hospital, Royal Perth Hospital, Dubbo Base Hospital, and Inner and Eastern Health Care Network (including four sites, and a Private Breast Nurse) (SBN Project Team 2000). Sites employed seven SBNs in half-time (n=3) and full-time positions (n=4). Two SBN positions were previously established and the remainder were newly appointed. While only one rural collaborating centre existed, other centres worked with women based in regional and remote areas including Western Australia and Northern Territory. Three centres were quite large, with two having catchments >1 million people, and the third being one of three clinics servicing all of Western Australia. The rural collaborating centre was the Dubbo Base Hospital in New South Wales. With a catchment population of 115,000 and area of almost 200,000 square kilometres, the 170 bed hospital functioned as a referral centre for three area health services. The rural SBN (award level CNC) had the most clinical experience of all SBNs with 8 years in medical oncology. The Dubbo SBN was contracted for 37.5 hours per week.



demonstrated to be effective across diverse Australian conditions, including urban/rural and public/private healthcare settings. Thirdly, the '5 in 12' clinical pathway was considered acceptable by women, SBNs, and the healthcare team (Liebert, et al., 2003). Finally, the comprehensive descriptions give enough detail to be replicable, as well as providing a baseline from which to compare future nursing services.

However, there are problems and limitations to the NBCC SBN Demonstration Project and its clinical pathway. Although adherence to protocol was high within highly supportive healthcare systems, SBNs identified challenges in adhering to the clinical pathway. Additionally, authors alluded to potential difficulties in SBNs providing care without the full support of surrounding healthcare systems: "Unless the SBN role is both well understood and well received by the full range of treatment team members, SBNs will not be able to provide women with the continuity of care that is recognised to improve health outcomes" (SBN Project Team, 2000, p.35).

Furthermore, the transferability of the findings is limited due to the atypical features of the intervention sites. The sites were selected by way of "a competitive bidding process" which meant that well-resourced, high quality, and forward thinking centres were included, rather than standard healthcare settings. Thus, intervention sites were not typical healthcare settings as the collaborating centres were considered peer leaders in breast cancer care.

The NBCC Project left questions in its wake for rural practice in particular, with doubts about whether the model of care is a good fit for rural practice. For example, important differences were identified between metropolitan and rural practice, highlighted by the rural SBN's simple statement: "Rural sites vary enormously from urban" (SBN Project Team 2000, Appendix 64 p.187).

Furthermore, the acceptability and feasibility of this model of care in rural sites was brought under question as the rural SBN did not prove sustainable beyond the life

of the project. No details were given as to why this was the case, instead a footnote stated “the rural site was unable to sustain the SBN position on completion of the project” (SBN Project Team 2000, p.62). It may be this model is too resource intensive to be feasible for financially restricted healthcare budgets which are typically the norm and/or it was not truly acceptable.

In summary, few detailed descriptions of BN models or nursing practices exist within the literature. Although the NBCC SBN Demonstration Project is an important exception, its fit for rural settings has come into question as it was not sustainable and its application greatly differed. Evidence of suitable rural models of practice is needed by service planners. Therefore, this study will address this gap with comprehensive descriptions of breast nursing practices in rural settings.

### **1.2.2. Scant Evidence to Guide RBN Practice**

Even when there are models of care and descriptions of nursing practices along with clinical practice guidelines, real challenges exist in translating research evidence to real world practice, particularly in Australian rural and regional areas. It is possible that fewer BN roles exist in rural areas as there has been a void of relevant information on how to design effective BN roles for these settings (Redman et al., 2003).

Translation of BN evidence to everyday practice may not happen for a number of reasons. Firstly, the resources required to change practice are often not available within limited health budgets. Indeed, the availability of resources may limit the translation of breast cancer evidence to practice, including the BN (NBCC and NCCI 2003). Secondly, the type of international evidence compiled may not be easily transferrable or relevant to Australian healthcare contexts. This has certainly been the case for BN learnings (Redman, et al., 2003). Furthermore, Australian studies are typically undertaken under trial conditions which do not reflect standard care settings, again making evidence translation challenging (as was the case with the NBCC SBN Demonstration Project). Finally, local circumstances related to individual

settings each bring up their own set of challenges (NBCC and NCCI 2003, p.85; Parle, et al., 2001). For example, the literature highlights practical challenges in evidence-based BN implementation related to logistical issues (SBN Project Team 2000; Szwajcer, et al., 2004).

Rural settings face additional challenges to implementing BN evidence. First and foremost, there has been little BN research aimed at rural areas. This is consistent with oncology health services research more generally (Campbell et al., 1999). "A clear finding from the literature was that getting evidence into practice needs to be context-specific and yet very little research has been conducted into the rural and remote context" (Parsons et al., 2003, p.242). There is scant evidence available to guide models of BN care for rural and regional Australia. This is especially true as urban evidence is unlikely to be transferable to diverse rural settings, and little has been reported in the scientific literature about how BN models could work in non-metropolitan or non-specialist cancer clinic areas. Therefore, few research findings provide direction into how rural BN models can effectively function in rural or low population areas.

While there is a small amount of international academic literature about rural breast nursing practices (for example: Carnwell & Baker, 2003a; Carnwell & Baker, 2003b; Carnwell & Baker, 2003c), little insight is provided as the 'rural' circumstances greatly differ from those found in Australia. For instance, the travel distances are much shorter, and the healthcare landscape is much less diverse within each country as compared to the Australian context. However, valuable learnings come from supportive cancer nursing roles in the Canadian context due to its similarity to Australian contexts (see: Howell, et al., 2008), and one rural Australian BN study (see: Eley, et al., 2008).

Rural sites also face additional systemic and logistical challenges to implementing best practice models. Importantly, these challenges are not typically addressed in evidence arising from metropolitan areas. Systemic challenges include issues such as limited mental health professionals for referral, difficulties providing appropriate

supervision, and smaller caseloads (CPRH Division 2003; SBN Project Team 2000). BNs have also identified logistical challenges specific to Australian rural contexts. Logistical issues include physical distances requiring clients travel for consultations and/or fewer face-to-face consultations (SBN Project Team 2000; Victorian Centre for Nursing Practice Research, 2001). Additionally, coordinating care can be complex as clients are often treated at more than one site, between which communication is often less than ideal (Victorian Centre for Nursing Practice Research, 2001). Yet, these rural challenges are not addressed in the available evidence.

Thus, published research findings typically provide an image of how BNs would undertake their work in a metropolitan best practice context. BN interventions are typically trialled in settings that are more highly resourced and supported than usual rural healthcare contexts. Therefore, the translation of this evidence into real world rural practice has proven difficult. Moreover, the image of BN models of care and outcomes emerging from the research may be an idealised version which is unrealistic in a large proportion of Australian healthcare settings which do not enjoy best practice contexts, despite the best efforts of BNs and/or service planners.

So, although the BN evidence was summarised in clinical practice guidelines for ease of implementation generally, its transferability is not straightforward. Translating evidence to practice is resource intensive. Also, evidence from different contexts can be difficult to transfer, and local contextual barriers can inhibit the uptake of best practice. Furthermore, rural contexts face a dearth of information about how rural practices can function effectively, along with their own set of systemic and logistical challenges. The reality is that real world nursing practices - and translating best practice to real world practices - is challenging and complicated.

In summary, the BN evidence has major gaps hampering its applicability to rural BN service development (van Driel et al., 2005). More rural health services research has the potential to guide the way forward in designing and implementing effective

health services in rural areas (Begbie & Underhill, 2007). Therefore, this study addresses this gap with evidence from rural contexts that reflects and acknowledges rural diversity and rural specific challenges.

### **1.3. Research Approach**

This study aims *to advance knowledge of rural breast nurses' practice within real world contexts*. A conceptual framework for RBN practice is developed by investigating elements of rural breast nursing practices, and the influences of client, contextual and nurse features on breast nursing. This health services research views RBN services more broadly than their interventions directly with women. With pragmatism as the guiding philosophical perspective, a mixed methods approach is used to gain a comprehensive description of and explanation for rural breast nursing practices.

A generic nursing conceptual intervention framework (detailed in Chapter Three) highlights the interrelationships between client, nurse, intervention, and context. Furthermore, it emphasises how client, nurse, intervention and context all impact nursing practices and outcomes. This conceptual framework provides the basis for the overarching question guiding this research:

**What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?**

This main research question is addressed through answering the following sub-questions:

- a) To what extent do women consulting RBNs have their supportive care needs met?**
- b) What are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?**

**c) How do RBNs describe their nursing practices, and what factors influence their practices?**

The research design is sequential, explanatory and mixed method. Quantitative elements provided the description while the qualitative element provided RBNs' perspectives on why they were that way. Together the research strands led to deeper understandings about breast nursing practices in rural settings. While this thesis does address the research questions to inform nursing services, it does not provide a prescriptive model for RBN practice (i.e. 'one size fits all approach').

Five sources of data were used to describe and explain rural breast nursing practices. Data was provided by clients and RBNs, with seven RBNs representing 3 RBN sites. Collection tools included Consultations Logs, Day Logs, Study Patient Lists, and semi-structured interviews with RBNs. Additionally, RBN clients completed Supportive Care Needs Surveys at two time points. Furthermore, results from this study were compared to similar data elsewhere to gain a better understanding of the findings. The researcher's experience and knowledge of the area, through involvement in a professional capacity and familiarity with the RBNs interviewed supported the data collection process.

Data analysis included both qualitative and quantitative processes. The quantitative analysis primarily relied upon descriptive statistics whereas the qualitative analysis utilised thematic analysis. Quantitative data analysis was supported by the use of Statistical Package for the Social Sciences (SPSS) software.

Based upon the data analysis and findings from this study, this thesis provides a conceptual framework for breast nurses' practice in rural settings. This framework highlights the influence of RBN and context in shaping nursing practices, whereas previous discourse was limited to women's impact on practice. Additionally, the importance of available and accessible features for clients, RBNs, and healthcare systems identified this concept as particularly influential in determining the effectiveness of RBN services.

### **1.3.1. Thesis Structure**

This study sheds light on breast nursing practices in rural settings based upon the quantitative outcomes of RBN clients, quantitative and qualitative descriptions of nursing practices, and comparisons to results of other studies.

The next chapter reviews relevant literature on breast nursing practices.

Importantly, it highlights a lack of published scientific literature to inform ‘real world’ nursing practices, and a lack of appreciation for the influences of context on nursing practices in particular. Chapter Three presents the pragmatic philosophical perspective and generic nursing conceptual intervention framework used in this thesis. Chapter Four describes the mixed methods design used to collect and analyse data to address the research questions. Chapters Five, Six, Seven, and Eight present the results and findings. Significantly, each results chapter addresses a sub-question of this thesis. Chapter Five answers the question: *to what extent do women consulting RBNs have their supportive care needs met?* Chapter Six answers: *what are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?* Chapters Seven and Eight answers: *how do RBNs describe their nursing practices, and what factors influence their practices?* Chapter Nine discusses the study findings while developing a conceptual framework for RBN practice, supported by the broader literature and answers the overarching thesis question. Chapter Ten concludes this thesis by demonstrating how the research aim was met and providing recommendations based on the findings.

## **1.4. Chapter Summary**

There is substantial social and political interest in breast cancer issues given the considerable burden of disease on a population level, and the major impacts on individuals’ lives. Supportive cancer care has significant backing from the scientific literature and consumer groups. BNs are heralded as providing major

improvements to women's cancer journeys. Yet, the lack of published literature to inform 'real world' nursing practices is an important impediment to implementing effective and sustainable RBN services in rural areas. Additionally, the context of practice is typically left unconsidered in the BN literature. A comprehensive description of rural breast nursing practices would benefit those attempting to implement such services. The next chapter will consider how BN literature has largely been unhelpful at informing effective and appropriate nursing practices in rural settings.

## **Chapter Two: Literature Review – What is Known, and What is Missing**

This review of the literature details what is known about breast nursing. Specifically, the review includes the definition of the BN role, the variability that is evident in actual practices, and the core elements of breast nursing which have been shown to be beneficial and in what ways. This is followed by an identification of the gaps in the literature which have led to the research questions of this study.

Despite the lack of a universal definition of BNs, definitions typically emphasise the aim of supporting women's physical, psychological, and psychosocial well-being over a period of time. Core elements of Australian breast nursing include the provision of information and emotional support, facilitation of coordinated care and continuity, and clinical care. The manner in which care is provided also is central to effective nursing, specifically a collaborative and interactive approach. Research has played an important role in defining core breast nursing practices.

Although systemic reviews have been inconclusive, extensive research findings have defined what BNs have done to support women, and the benefits of BNs involvement in women's care. Research describes what BNs do, and how they do it. The identified actions and benefits of BNs – for both women and treatment teams –



are summarised in clinical practice guidelines in order to enable the translation of evidence to breast nursing practice. The benefits for women include psychosocial, physical, satisfaction with care, and continuity of care. However, as the previous chapter highlighted, less research is available to describe and inform breast nursing practices especially in rural settings.

This chapter will demonstrate there are gaps in the literature which could effectively inform rural breast nursing for the betterment of their clients and the healthcare team. Comprehensive assessments of cancer care are needed which more fully describe practice. The context in which care is provided, and how this relates to nursing practices, has generally been absent from discussions, as has the person who undertakes the BN role. Effectiveness in 'real world' practice needs further exploration.

## **2.1. Defining the Breast Nurse Role and Breast Nursing**

The definition of the breast nurse role used in the thesis is as follows:

“... a registered nurse who applies advanced knowledge of the health needs, preferences and circumstances of women with breast cancer to optimize the individual's health and well-being at various phases across the continuum of care, including diagnosis, treatment, rehabilitation, follow-up and palliative care.” (Yates et al., 2007, p.13)

It is important to clarify how the term breast nurse (BN) role will be used in this thesis, since there is variation in the literature and no single recognised definition of the role. Some definitions provide an overarching aim of the role, while others detail elements of nursing practice or 'what the nurse does'. There is a great deal of blurring of these elements of the definition in the literature. In this thesis, the term 'role' will be used to refer to the overarching aim of the BN, rather than the elements of breast nursing practice which are discussed next.

A useful international definition provided in a recent Cochrane review stated that BNs' supportive care interventions aimed to improve a woman's quality of life – including physical, psychological, and psychosocial elements (Cruickshank, et al., 2008, p.72). This definition is succinct and encompasses the key aims of the role found in the literature.

The definition provided at the beginning of this section is a more comprehensive Australian definition put forward by the NBCC. This definition, while still providing an overall aim, provides detail about who undertakes the role and the advanced knowledge they need. Importantly, it indicates the role provides care over time, namely across important points in the breast cancer journey. This definition is the most client-centred of those in the literature, and is used in this thesis as a basis for understanding the BN role.

Australia has gone from having no role definitions to a selection of BN definitions in the last 10 years (for example see Hordern, 2000). The clinical practice guidelines included definitions of breast nursing, as did the NBCC SBN Demonstration Project (NBCC and NCCI 2003; NHMRC NBCC, 1999; SBN Project Team, 2000). Earlier definitions were useful for those attempting to implement the BN role, but the recent NBCC definition better reflects the current Australian directions in nursing roles.

While one agreed definition is lacking, many definitions of the BN role emphasise:

- the aim to support the woman's physical, psychological and psychosocial wellbeing,
- care over time or 'across the continuum',
- the central role of providing information and support, and
- the need to work collaboratively with other health providers in the care of their clients (Cruickshank, et al., 2008; Eicher, 2010; Liebert, et al., 2001; NBCC and NCCI, 2003; SBN Project Team, 2000; Yates, et al., 2007).

The first two elements are part of BNs' overarching aim whilst the second two could and will be considered as part of breast nursing practices in this thesis. Essentially this division between definitions of role and core nursing practice is somewhat artificial, as they are invariably linked. But core nursing practice involves a large amount of detail about what nurses do, and for the purposes of clarity and readability this is dealt with later in this chapter.

Definitional variations are likely to have arisen from differences in cultures, geography, and health system context. For example, definitions have been influenced by the varying experiences, knowledge, and interests of people consulted during definition development. Also the types of roles which already existed influenced the way the BN role has been defined. Some of the definitional variations have arisen from an evolution in ideas about the BN role over time. Whatever the causes of the variations, the variability creates difficulty when looking at the literature around BNs. It is not easy to compare 'apples with oranges'.

Differences in breast nursing practice definitions are viewed as primarily semantic. Following a diagnosis with breast cancer, the BN is often the primary contact for women and therefore the BN is in a prime position to impact her clients' health and wellbeing (Cruickshank, et al., 2008). What happens in these consultations with clients, and BNs work with health professionals and other services, constitutes the core dimensions of breast nursing. Within the literature, definitions include the core elements of breast nursing along with the manner in which the nursing is undertaken.

As was the case with BN role definitions, there are a plethora of breast nursing definitions, which have evolved through time. In the late 1990s, elements of Australian breast nursing were described for the first time (White & Wilkes, 1999a). The key themes emerging from this qualitative study were specialist nurse, supporter, educator, counselor, advisor, team member, resource person, caregiver, public advocate, manager and researcher. Researchers noted the components merge in real practice.

While all of these previously defined breast nursing elements continue to be perceived as valuable, some are no longer stated as core dimensions of breast nursing in more recent definitions<sup>5</sup>. Some elements are part of some breast nursing at some sites but certainly not universally accepted, such as the manager element. Other elements have been collapsed into broader themes of breast nursing in more recent definitions. For instance, the elements of educator, resource person, and advisor can all be considered components of providing information to clients and health professionals.

More recently, core dimensions of Australian breast nursing were identified by the NBCC (NBCC 2005)<sup>6</sup>. The core elements of breast nursing are listed as:

- providing information, resources and education;
- providing psychological and emotional support;
- facilitating coordination of services and continuity of care; and
- providing clinical care.

These are the core dimensions of breast nursing adopted within this thesis, and are discussed in detail later in this chapter.

Despite a variety of breast nursing definitions in recent years, most point to the same core themes as NBCC with some semantic differences. For example, many definitions place the BN as a participating member of a multi-disciplinary team (Eicher, 2010; Liebert, et al., 2001; NBCC and NCCI, 2003), while others instead emphasise collaborating with other healthcare providers (SBN Project Team, 2000). Yet, the collaborative and interactive nature of breast nursing is the underlying theme running through both. Essentially, both definitions envision the BN working in collaboration with other providers to enable the best possible outcome for their shared clients.

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<sup>5</sup> The clearest example is that participating in research is no longer considered core to breast nursing (for example see: SBN Project Team, 2000).

<sup>6</sup> This was done in the process of developing national competency standards for BNs.

In essence, many of the apparent differences in breast nursing descriptions are about the *manner* in which the core elements are undertaken to fulfil the BN role (i.e. aiming to optimise client's health and well-being). When considered more closely, it is clear there is much consistency in the manner BNs are expected to undertake breast nursing. These include the collaborative and interactive nature identified in the previous paragraph. 'Being a resource for other health professionals' also fits nicely within this general approach, and corresponds with the core elements of providing education and facilitating continuity of care (SBN Project Team, 2000; White & Wilkes, 1999a). Although all breast nursing includes supporting women with breast cancer, while some specifically point to supporting and educating family members and significant others (NBCC and NCCI Eicher, 2010; 2003), all aim to improve client well-being using an interactive and collaborative approach.

Breast nursing definitions have at times also incorporated other elements such as counselling and providing advice (NBCC and NCCI 2003; SBN Project Team, 2000; White & Wilkes, 1999a). BNs provision of counselling to women is contentious for some, as is the provision of advice. In the Australian context, recent literature typically refers to supportive care or emotional support rather than counselling, as counselling is often considered a task for mental health specialists rather than nurses. Advice is another contentious activity, which has received cautious use more recently with initiatives promoting patient-driven care.

Although the term 'breast nurse' is used to cover the various role titles and nursing practices, it is inevitable given the variations in context that BNs will have some differences in nursing practices. This variability is discussed next with regard to inconsistencies in titles, educational preparation, practice levels, and settings.

## **2.2. Variability in Real World Roles and Practices**

Variability in role enactment is not uncommon for advanced practice nurses.

Practicing in a range of health care settings, with different and changing clientele

groups necessitates emphasising different skills (Kudless & White, 2007). Nurse practitioner roles and practices are identified as developing differently “according to the needs of specific practice settings and the resources available within them” (Elsom et al., 2005, p.183). Similarly, a mixed method study reported prostate cancer nurses vary in practices and services provided across sites (Ream, et al., 2009).

Extensive variability is reported in real world breast nursing. Variability is evident in the organisation, scope, and enactment of breast nursing. Efforts to standardise nursing practices are driven by the desire to ensure consistent outcomes. However, some variability in care is necessary to reflect different women’s needs, care plans, local circumstances, nurses’ expertise, and the complementary nature of the role. Therefore, a conceptual framework informing effective and sustainable breast nursing practices is likely to be more useful than a prescriptive model.

The organisation of breast nursing varies widely in real world practice. The scope of BN practice is highly variable, as is how the role is enacted (Tait, 1995; White & Wilkes, 1999a). There is extensive variation in how BNs operate across settings and with different RNs (Victorian Centre for Nursing Practice Research, 2001; White & Wilkes, 1998). Within Australia specifically, there is extensive variation in the enactment of breast nursing (Campbell, et al., 2006; Jones et al., 2010; White & Wilkes, 1998). This variability is found in levels of nursing practice, titles, practice settings, and involvement in the cancer journey.

First, disagreement exists around whether the BN is a specialist nurse and/or advanced practice nurse (White & Wilkes, 1999a). Specialist nursing deals with a defined population or area of focus, whereas advanced practice involves greater complexity and autonomy (iSource NBCC 2003). Although BN care happens on different nursing levels, these are often not made transparent in the literature. For instance, the incumbent’s nursing level might not be stated (for example see: Halkett et al., 2006; Jiwa et al., 2010). A lack of clear distinction in BN levels of practice has historically confounded understandings of the BN, and may have

contributed to the confusion and diversity present in practice. In recent years, steps were taken in Australia and the United Kingdom delineating levels of breast nursing, and their intertwining with nurses' skills, knowledge, experience, and education (NBCC 2005; RCN 2007; Yates, et al., 2007).

Next, the title of the BN role is also highly variable. Although titles might seem superficial, titles are important as they are meant to imply levels of practice. At least 14 titles were found of RNs who considered themselves breast care nurses (Victorian Centre for Nursing Practice Research, 2001). Most commonly in Australia, the BN role has been titled specialist breast nurse (SBN) or a breast care nurse (BCN). Generally SBNs are considered more experienced or senior roles and the BCN is either a generalist or junior role, although this is not always the case (Szwajcer, et al., 2004). While the NBCC<sup>7</sup> regularly uses the SBN title, the BCN title is still commonly used by others in Australia (Eley, et al., 2008; Halkett, et al., 2006; Liebert, et al., 2003; Liebert, et al., 2001; Szwajcer, et al., 2004; Yates, et al., 2007). Moreover, often the literature does not define the level of education or training of those holding the roles (for example see: Jiwa, et al., 2010; Szwajcer, et al., 2004).

Inconsistencies between BN titles, practice levels, and/or education and training are common, and serve to complicate the matter. A nurse entitled a BCN in one area might be working at an advanced practice level, whereas in another area a nurse with the same title works at a lower level. For instance, one position given the BCN title was employed at one of the highest level of clinical nursing as a clinical nurse consultant (Szwajcer, et al., 2004), while another nurse entitled a SBN was a registered nurse on a general surgical ward (White & Wilkes, 1999a).

Diversity is also present in the range of BN practice settings. BNs hold a wide variety of positions across various locations within the healthcare system (Hordern,

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<sup>7</sup> The National Breast Cancer Centre became National Breast and Ovarian Cancer Centre (NBOCC) in 2008. NBOCC amalgamated with Cancer Australia in 2011 to form a single national cancer agency.

2000; Victorian Centre for Nursing Practice Research, 2001). Consequently, nurses place more or less emphasis on different aspects of the role depending on the setting and the relevant client needs (Burnet et al., 2004). For example, BNs working from a surgical ward are more likely to focus their role around surgical intervention, such as treatment decisions, surgical preparations, and recovery. As BN positions are in public and/or private healthcare systems, and in urban and rural settings, “the components of the role have different emphases depending on the location and funding mechanism” (Szwajcer, et al., 2004, p.80).

Finally, a major discrepancy in BN practice is the extent of involvement in the women’s cancer journey. There is wide variability in the breadth and length of support provided by BNs (Campbell, et al., 2006; White & Wilkes, 1999a). A continuum of breast nursing approaches exists, ranging from comprehensive to fractional care. Comprehensive care assists women to navigate the full continuum of breast cancer illness / treatment trajectory, extending from diagnosis through to follow-up, and possibly even including palliation. Fractional care focuses on a select time period within a women’s breast cancer diagnostic or treatment trajectory. Examples of fractional care include supporting women through screening and diagnosis or pre to post-surgical intervention. Although a continuum exists, BN services typically follow either a fractional or comprehensive approach (Eicher, 2010).

Fractional care is the reality of Australian breast nursing practices in the majority of instances. Of the 48% of Australian women with breast cancer who consulted a BN, 32% saw a BN only once or twice (20% and 12% consecutively) (Campbell, et al., 2006). Indeed, comprehensive care is uncommon. Only 16% of Australian women reported seeing a BN on at least three occasions, while only 11% reported having received consultations during at least pre-operative, post-operative, and follow-up periods (Campbell, et al., 2006). Moreover, unstructured clinical pathways characterise usual care practices in Australia (Campbell, et al., 2006; Victorian Centre for Nursing Practice Research, 2001).



### **2.3.1. Striking a balance between Standardisation and Flexibility**

Concerns have been raised about a possible divergence of outcomes for women given the varied scope of breast nursing practices, models implemented, levels of practice, and the range of skills, education and expertise of BNs. Minimising variability through the standardisation of breast nursing practices in Australia (e.g. through competency standards and education programs) has been recommended as a means to ensure quality and consistency in outcomes for women. For example, competency standards are seen as a “first step in addressing the issues of role variation amongst nurses” (Yates, et al., 2007, p.14). Additionally, care pathways and models of care can presumably ensure standardisation of outcomes and quality practice (SBN Project Team 2000; Yates, et al., 2007). However, there is tension in the literature between the utilisation of structured BN clinical care pathways, and allowing for flexibility and diversity in the role to appropriately respond to the healthcare context and clients’ needs. Indeed, a certain degree of variability in breast nursing practices may be necessary<sup>8</sup>.

The need for flexibility in breast nursing arises from core aspects of the role, namely its responsive and complementary nature, and human elements. Responsive BN care is necessarily individualised and patient-centred. This is consistent with supportive cancer care more generally (Verhoef et al., 2007). Specifically, necessary variability in nursing practices is driven by individual women’s needs (SBN Project Team, 2000; Burnet, et al., 2004; Tait, 1995) and diverse care plans (SBN Project Team, 2000; Campbell, et al., 2006). The complementary nature of the role results in a morphing of nursing practices to fit local circumstances, such as existing support networks (SBN Project Team, 2000; Burnet, et al., 2004; Halkett, et al., 2006; Szwajcer, et al., 2004; Tait, 1995). Similarly, community supportive cancer

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<sup>8</sup> However, variable working patterns will continue to make it difficult to assess service equity and quality, and make contribution to care unclear (Ream, et al., 2009). Furthermore, the variations in roles across practice settings make identifying and quantifying what BNs do challenging (Cruickshank, et al., 2008).

care nurses adapted their practices to accommodate gaps in the wider health system (Howell, et al., 2008).

The human element of breast nursing also leads to inevitable variability. Not only are BN interventions bounded in nurse-client relationships (Jiwa, et al., 2010), but varying nurse expertise will inevitably lead to variations in practices (Aydelotte, 1984; Tait, 1995). Essentially, “the support of a woman with breast cancer cannot be prescriptive but is variable, individual and constantly changing” (Wilkes, Beale, et al., 1999, p.72). The variability observed in breast care delivery may be necessary to achieve benefits across various healthcare and organizational contexts, and ‘team’ compositions.

Therefore, although structured clinical pathways are helpful to assist BN service planning and ensure quality outcomes, one model of care might not be ideal for the diverse range of Australian healthcare contexts. Instead a conceptual framework may be more useful to those planning and providing BN services than a fixed approach. Notably, this tactic was used for multidisciplinary care “because of the diversity of healthcare service delivery settings and models of care in Australia, it is not appropriate to have a fixed approach” (Zorbas et al., 2003, p.530). Evidence-based principles are then translated into local practice which enable and ensure high quality services. That is, modifications are made to care pathways to enable locally appropriate breast nursing practices.

### **2.3. Describing the Elements of Breast Nursing Practice**

The research base has played a major role in developing and defining breast nursing. This section summarises the literature that describes what BNs can do and in what ways the women who consult with BNs are understood to benefit. The section starts by providing an overview of the research base including systemic reviews of breast nursing. Then, the BN actions described as helpful and effective in the literature are detailed, along with the specific interventions BNs can undertake and the apparent outcomes resulting from BN involvement. Knowing what the

nurse does in her efforts to fulfil the BN role is important in understanding and replicating its effectiveness. This section ends with a critical analysis of the literature to date.

### **2.3.1. Research Overview**

While much of the research foundation is from the UK, Australian research has contributed to understandings of breast nursing and its outcomes more recently. The research results, in combination, have formulated the highest level of evidence recommending BNs involvement in the care of women with breast cancer in Australia. Although systemic reviews have been inconclusive, there is a substantial amount of research supporting the benefits of BN interventions and potential outcomes.

The seminal research on breast nursing originated in the UK, and the majority of evidence substantiating the benefits of breast nursing comes from the UK context. Research on the effects of nurse counselling for breast cancer patients laid important foundations for the role (Maguire et al., 1983; Maguire et al., 1980; Watson, 1988). This was followed by McArdle et al's (1996) randomised control study assessing psychological morbidity of women consulting a BN as compared to other care options. These provided demonstration of reduced psychological morbidity for women linked with specific nursing interventions.

Scientific literature about the BN has emerged from Australia in the last 20 years, and more recently from Scandinavia. While UK breast nursing research tends to focus on the time of diagnosis and earlier care, the Scandinavian research has centred on follow-up care. The most comprehensive research undertaken in the Australian context is the NBCC's multicentre implementation study, the SBN Demonstration Project (Liebert, et al., 2003).

Australian clinical practice guidelines recommending women's access to SBNs primarily rely on level I and level II evidence (NBCC and NCCI, 2003; NHMRC NBCC,

1999). Five randomized control trials demonstrated that SBNs could improve women's understanding, recall, satisfaction with care and continuity of care (Clacey, et al., 1988; Maguire, et al., 1983; Maguire, et al., 1980; McArdle, et al., 1996; Watson, 1988). Breast nursing can reduce psychological morbidity and anxiety as well as increase the identification of women with depression (Redman, et al., 2003). Also, the beneficial effects of psycho-educational care have been established with a strong research base (Devine & Westlake, 1995), and this care has been effectively provided by BNs to women with breast cancer.

### **2.3.1.1. Systemic Reviews of Breast Nursing**

Rigid evidence for the effectiveness of breast nursing has been inconclusive. Systemic reviews of evaluations of the effectiveness of BNs have been hampered by the challenges in comparing different roles (Eicher, et al., 2006). Two systematic reviews found unclear results of the efficacy of BNs, primarily related to a lack of consistent role definitions and practice, as well as weaknesses in research methodologies (Cruickshank, et al., 2008; Eicher, et al., 2006). However, the use of traditional evaluation techniques such as the randomised controlled trials are not a good fit for the assessment of a developing model of care due to the model's iterative nature (Davidson, et al., 2006). Nonetheless, strong early evidence of positive outcomes laid the foundation for key breast nursing interventions.

The first systemic review indicated specialised nurses in breast care may contribute to improvements in physical and psychosocial well-being (Eicher, et al., 2006). The review included 10 studies which described and analysed specialist nursing for women with breast cancer and found in the scientific literature between 1980 and 2006. The diversity of definitions constituting a BN, along with the variety of models of care, competence and educational levels, work domains, and levels of autonomy limited the generalisability and comparability of the results, as did their restricted search method (e.g. limited to comparative designs). Nevertheless, Eicher and colleagues classified outcomes in six dimensions (Eicher, et al., 2006, p.3124). While improvement of physical impairment reflected varied results, the

review found specialist nurses generally demonstrated positive effects on improvement in psychosocial problems, decision making processes, patient satisfaction, and collaboration in multi-professional teams. No differences in costs of care were identified.

A Cochrane Review assessing BN interventions effectiveness on quality of life outcomes was limited to randomised controlled trials (Cruickshank, et al., 2008). Five studies met the inclusion criteria. The review included psychosocial and supportive care interventions, along with nurse-led follow-up interventions, and encompassed interventions covering various treatment phases in the disease trajectory (namely, diagnosis, early treatment, radiotherapy, and follow-up) (Koinberg, et al., 2004; Maguire, et al., 1980; McArdle, et al., 1996; Ritz et al., 2000; Wengström et al., 2001). The review found BN interventions could impact quality of life indicators such as anxiety and perceived distress, while other differences in indicators such as coping skills, mood, and social and functional aspects of the disease trajectory were either inconclusive or unchanged by BN interventions.

The conclusions of the Cochrane Review, based on the findings of five randomised controlled trials, were that limited evidence was available to identify the particular BN interventions that impact on quality of life, and that more research is needed. However, the Review did find that the nature of BN work within a cancer care team “serves to complement the team as a whole rather than highlighting the impact of the BCN alone” (Cruickshank, et al., 2008, p.9). This emphasises the need for breast nursing to fit within the local context, and whatever constitutes ‘the healthcare team’ in that context. Yet, there are weaknesses in relying on randomised controlled trials as they “focus on the presumed active component of interventions, often discounting synergistic effects, and assess how efficacious the intervention is under ideal experimental conditions rather than real world conditions in which cancer care occurs” (Verhoef, et al., 2007, p.906).

Nevertheless, extensive research, including randomised controlled trials and descriptive studies, has demonstrated the potential benefits of breast nursing. BN

interventions have led to benefits for women, and for the healthcare team. “A significant body of evidence demonstrates that the provision of information and psychological care improves functional health, emotional adjustment and satisfaction with care in cancer patients” (NHMRC NBCC, 1999, p.47).

The below sections summarise the research by describing the interventions BNs and other health care providers could use which have demonstrated positive results for women, followed by the beneficial outcomes resulting from these interventions.

### **2.3.2. Provider Practices that are likely to Help**

There is Level II evidence that SBNs provide continuity of care throughout treatment phases for women with breast cancer (Clacey, et al., 1988; McArdle, et al., 1996; National Breast Cancer Centre and National Cancer Control Initiative, 2003; Watson, 1988). Level II evidence also demonstrates that having discussions with a SBN reduces psychological morbidity, and increases understanding of breast cancer, recall of information and perceptions of support for women with breast cancer (Clacey, et al., 1988; Maguire, et al., 1983; Maguire, et al., 1980; McArdle, et al., 1996; National Breast Cancer Centre and National Cancer Control Initiative, 2003). These are certainly positive assertions regarding SBNs, but they provide little insight into how SBNs could bring about these patient benefits.

It is important to understand which interventions can lead to positive outcomes. Knowing what BNs could do, and how they could do it, presumably enables favourable outcomes to be replicated. As outlined earlier in this chapter, the core dimensions of breast nursing are: information provision, support, coordination and continuity of care, and clinical care. These dimensions are recurrent themes in the literature, which capture a multitude of interventions. This section describes the breast nursing practices identified in the literature that BNs can and/or do use to bring about positive results for their clients.

While some of the evidence comes from BNs and women with breast cancer, other evidence is derived from other health professionals and/or people being treated for

other types of cancer. The *Clinical practice guidelines for the psychosocial care of adults with cancer* summarised the evidence on which practices provide positive psychosocial outcomes (NBCC and NCCI 2003). Breast nurses can use the following practices which studies have demonstrated the potential to help clients: general interactional skills, discussing prognosis, providing information and choice, preparing for potentially threatening procedures / treatments, emotional and social support, ensuring continuity of care, support towards the end of life, exploring and responding to specific concerns, and the referral and treatment of anxiety and depression (NBCC and NCCI 2003). These practices fit neatly within the overarching core dimensions of breast nursing.

How BNs go about what they do, is also important. Qualitative research has led to insights in how BNs go about the core dimensions of breast nursing. Qualitatively derived themes have shed light on the approaches and means used to bring about positive outcomes (for example: Halkett, et al., 2006; Jiwa, et al., 2010). Much earlier, Denton (1996, p.12) eloquently summarised the qualitative aspects of the *caring* work of breast nursing including compassion, competence, conscience, commitment, and confidence.

As highlighted earlier, the core dimensions of breast nursing are: information provision, support, coordination and continuity of care, and clinical care. The activities undertaken to address these core dimensions are described below.

#### **2.3.2.1. Information Provision**

There is Level I evidence demonstrating the provision of appropriate and detailed information to people with cancer promotes understanding and increases psychological wellbeing (Devine & Westlake, 1995; National Breast Cancer Centre and National Cancer Control Initiative, 2003). This has been demonstrated repeatedly, attaining the most highly regarded level of evidence in Australia (i.e. NHMRC Level 1)(Devine & Westlake, 1995). Additionally, Level I evidence demonstrates that patients' recall of information increases when adults with cancer

are provided with individualised information (National Breast Cancer Centre and National Cancer Control Initiative, 2003; O'Connor et al., 1999).

Information provision is a core dimension of breast nursing. Many claim BNs are in a good position and have the skills to provide high quality individually-tailored information, which is staged (i.e. distributed at appropriate points in the journey rather than all at once) and timed appropriately and in response to women's preferences. This includes preparing for procedures, informing of relevant schemes and services, and clarifying information from specialist consultations. Additionally, BNs may be in a position to reinforce information provided by specialists, and serve as a resource for healthcare professionals.

To do this, BNs would need to identify high quality written resources for their clients. An extensive range of information is available about breast cancer from a variety of sources, but not all resources are of a good quality. However, BNs may be well placed to determine the quality of information resources, and propagate the distribution of those that are high quality. As information popularity and accessibility does not necessarily equate with its quality, this is especially important in the area of breast cancer (Purcell et al., 2002). BNs can also provide high quality information in ways that are useful and timely for women.

There are a range of evidence-based strategies available for BNs and other health care providers to effectively and sensitively provide relevant and timely information to women. They can assist their clients by routinely providing a combination of verbal and printed material relevant to the client's individual experience (Devine & Westlake, 1995; White & Mcleod, 2002). One study reported BNs typically provided information about breast cancer, diagnosis, clinical trials, reconstructive surgery, and treatment, including the processes and possible side effects (SBN Project Team 2000). Ideally information is individualised, that is, tailored for each individual woman and her own experience (O'Connor, et al., 1999). If possible, BNs and other health care providers should try to enable a woman to receive her results as soon as possible, including a written record of her results to help her remember the results



and improve her satisfaction with her care (Patterson & Teale, 1997). Importantly, health care providers should stage information to people with cancer, while checking clients' understandings as well as their desire to hear more (National Breast Cancer Centre and National Cancer Control Initiative, 2003; White & Mcleod, 2002). Although concern has been raised that women may be too anxious or distressed to receive information at diagnosis, research suggests women with breast cancer appreciate receiving information at this time to inform treatment-related decisions (NHMRC National Breast Cancer Centre, 1999).

Research also suggests BNs may be able to assist clients with practical issues such as preparing women for upcoming procedures and making them aware of relevant schemes. In one Australian study conducting in-depth interviews with 18 women who had completed early breast cancer treatment, women reportedly found the provision of practical information by BNs very useful (Halkett, et al., 2006). One study indicated this information could pre-empt problems for women, and in some instances enable their prevention, although this study was limited to the follow-up time period i.e. after initial treatment (Jiwa, et al., 2010). One seminal study, laying the foundation for NHMRC level II evidence, demonstrated that BNs can prepare women for upcoming procedures, including diagnostic tests and treatments (McArdle, et al., 1996). Numerous studies demonstrate the provision of information about procedures a client is about to undergo improves psychological well-being and physical recovery (Ganz, 2000; Hathaway, 1986; Johnston & Vogeley, 1993). Obviously, early referrals to BNs are necessary to enable the nurse to support the client's understanding of upcoming procedures. However, studies indicate early referrals to BNs can be challenging in certain contexts e.g. privately insured patients (Szwajcer, et al., 2004).

Some studies show BNs can provide information about relevant government schemes and services. For example, in one study BNs have been identified as a vital link in providing information and support for the government assisted breast prosthesis scheme (Livingston, et al., 2000). Informing clients of patient travel

assistance schemes may be especially important, particularly for those who are from rural or regional areas (McGrath, et al., 1999).

It has been suggested that BNs also support other healthcare providers' efforts to educate women, as well as being an important breast cancer resource for healthcare providers themselves. It may be that BNs support the work of specialists by reinforcing and clarifying information and client understandings from specialist consultations (e.g. surgeons and oncologists), as well as addressing questions that arise for women. Furthermore, several studies have indicated BNs are a resource for health professionals, with some studies showing BNs provide education and expert advice to other nurses and healthcare providers through formal and informal means (Amir et al., 2004; Carnwell & Baker, 2003a; SBN Project Team 2000; White & Wilkes, 1999a). Amir et al's (2004) study was based on in-depth interviews and observations of 16 multidisciplinary teams in England, while Carnwell et al's (2003) evidence emerged from 177 postal surveys to Practice Nurses and District Nursing Sisters in North Wales.

Significantly, BNs may be well-placed to provide information within a supportive context. "Effective communication... involves more than the provision of information; it requires a process of individually-tailored explanation, problem-solving and acknowledgement of the woman's feelings" (NHMRC NBCC 1999, p.7).

### **2.3.2.2. Support**

There is Level I evidence demonstrating that giving adults with cancer the opportunity to discuss their feelings with a member of the treatment team or a counsellor decreases their psychosocial distress (Devine & Westlake, 1995; National Breast Cancer Centre and National Cancer Control Initiative, 2003). Additionally, there is also Level 1 evidence demonstrating that adults with cancer provided with psychosocial support before undergoing surgery have reduced psychological distress (Meyer & Mark, 1995; National Breast Cancer Centre and National Cancer Control Initiative, 2003).

With high levels of psychological morbidity associated with a women's journey with breast cancer, providing psychological and emotional support is a cornerstone of breast nursing. It is thus not surprising that one study showed more support is received by women who consult a BN as compared to those that do not (Campbell, et al., 2006). However, the data was collected for this study in 1997, and supportive cancer care has since received significant attention e.g. inclusion in clinical practice guidelines. The recent literature suggests the support dimension of breast nursing includes supportive and empowering communication, and creating an environment where emotional concerns can be raised and addressed.

BNs may create the opportunity, and demonstrate willingness, for women and nurses to raise and address psychosocial concerns. In one Australian study describing patients' perspectives, women reported that the BNs availability was very important (Halkett, et al., 2006). Ideally, the time and space is made to review psychosocial needs, as well as perform psychosocial assessments. Issues discussed may include body image, sexuality, interpersonal challenges, coping and distress. As previously clarified, support provided by a BN is at a different level to that provided by a specialist mental health professional. Nonetheless, one seminal study (Maguire, et al., 1980) demonstrated BNs are able to detect and refer women having significant psychological difficulties to mental health specialists, leading to much less psychiatric morbidity 12 to 18 months following surgery (Maguire, et al., 1980). Indeed, Level I evidence demonstrates that referring clients with risk factors to specialised psychological services minimises their chances of developing significant distress (National Breast Cancer Centre and National Cancer Control Initiative, 2003). However, a more recent Australian study indicated SBNs referred few women to specialist psychology services due to access difficulties and low uptake by clients (SBN Project Team, 2000). General cancer patients also exhibit low psychological referral uptake for similar reasons (Curry et al., 2002). It may be that early interventions by BNs assist women to cope better, and can include for example relaxation techniques and managing fatigue.

Studies have shown women benefit from being able to discuss their feelings with a BN (Devine & Westlake, 1995). BNs may normalise a woman's experience and discuss her feelings and concerns within a trusting professional relationship (Jiwa, et al.). Some suggest it is comforting for women to know the things they might be feeling are common (White & Mcleod, 2002). One qualitative study investigating consultations between four SBNs and 21 consecutive clients indicated normalisation is an important breast nursing practice (Jiwa, et al., 2010). Importantly, this study highlighted BNs provide follow-up support "within the context of an established relationship" (Jiwa, et al., 2010, p.146). Although only 21 consultations were considered in this study, the researchers only ceased collecting data when saturation of themes was achieved.

Studies indicate that helping women to feel empowered in coping with breast cancer is important (Koopman et al., 2001). BNs may empower women to have more personal control over their disease and treatment. Jiwa et al (2010) found this was done by coaching and preparing women to ask questions of specialists. The researchers found the BNs encouraged their clients to take a pro-active approach, aiming to enable them to be less and less reliant on SBNs (Jiwa, et al.). Other researchers purport the need for designated nurses for all patients (not limited to cancer) that provide 'therapeutic interpersonal interactions' promoting perceptions of personal control and the associated emotional comfort, having the effect of enhancing recovery (Williams & Irurita, 2004). BNs may be the sort of designed nurse they were envisioning, being well placed to develop personal control in their clients, and contributing to client's emotional comfort (e.g. by BNs explaining treatment options to enable women to make informed choices).

A significant way BNs could empower women is to highlight their choices and support their involvement in decision-making. BNs may help women to understand they have choices, by ensuring women are aware they have a choice and understand the options. The literature indicates that cancer patients cope significantly better when offered choice as compared to receiving a definitive

recommendation (Butow et al., 1995). BNs can utilise best practice strategies to facilitate shared decision-making, such as those identified by Brown et al (Brown et al., 2002, p.236): “explicit agenda-setting, active listening, checking understanding, endorsing question-asking, offering decisional delay, and non-verbal behaviours conveying empathy and warmth.”

Several studies indicate women can benefit from the emotional and social support of the BN, and presumably her ability to explore and respond to specific concerns (NHMRC NBCC 1999). Australian women reported being able to talk to the BN and receiving emotional support while discussing their concerns had a helpful and positive impact on their breast cancer journey (Szwajcer, et al., 2004). One study found a BNs’ support is bolstered by the communication style they utilise, the rapport they develop with women, and their awareness of women’s needs (Halkett, et al., 2006). Indeed, studies have demonstrated that BN support can lead to decreased psychological morbidity and more rapid adjustment for women with breast cancer (McArdle, et al., 1996; Watson, 1988).

#### **2.3.2.3. Coordination and Continuity of Care**

As described in Chapter One, women may utilise a multitude of service providers and healthcare sites in their individual journey with breast cancer. Without coordination, this can result in fragmented care. As highlighted earlier, Level II evidence indicates SBNs provide continuity of care for women with breast cancer. It may be that the BNs in these studies were improving care through service coordination and patient navigation. The BN may work with care providers as a service coordinator (by referring and liaising) and with the woman as a patient navigator (by guiding and supporting). Services are coordinated by referring clients and working constructively with other healthcare professionals. Studies indicate that BNs facilitate the access to services for their clients, and work collaboratively with a group of health professionals supporting the care of women with breast cancer, often coordinating the group’s efforts. BNs may function as a guide

providing women with a detailed 'map', thereby empowering women to know what to expect and enabling them to navigate their own journey.

Guthrie and colleagues (2008) presented a convincing argument based on an analysis of the literature that continuity of care matters. Continuity of care is composed of 3 domains: informational, relational, and management (Haggerty et al., 2003). The BN, like the generalist supportive cancer care nurse described by Howell et al (2008) may enable all continuity of care domains, by providing information that shapes clients treatment decisions (i.e. informational continuity), maintaining an ongoing relationship with the client (i.e. relational continuity), and assisting in the coherent management of her condition (i.e. management continuity) (Guthrie et al., 2008; Howell, et al., 2008). Howell et al (2008) provided a useful qualitative and quantitative description of a generalist community supportive cancer care service provided by six nurses for over 700 clients over a one-year period in Canada. Importantly, "relationship continuity facilitates informational and management continuity when they matter most" (Guthrie, et al., 2008, p.548).

The BN can be a part of a multi-professional team providing care for women with breast cancer, regardless of whether the team is formalised or not. BN care is inevitably linked with other healthcare providers who share the care their clients, especially specialist clinicians. When multi-disciplinary teams are formalised, BNs have been shown to play an informal leadership role in ensuring coordination, planning and communication (Amir, et al., 2004). Amir et al's (2004) results were based on in-depth interviews and observations of 16 multidisciplinary teams in England. The NBCC SBN Demonstration Project found SBNs improved the functioning and efficiency of other health professionals through liaising and communicating with other treatment team members (SBN Project Team 2000). Studies indicate the information exchange and sharing BNs (and other supportive cancer nurses) can do between treatment team members, and between the client

and the treatment team is highly valued and leads to continuity of care (SBN Project Team, 2000; Howell, et al., 2008).

BNs can facilitate access to services for women using two main strategies (Jiwa, et al.). Similarly, community supportive cancer care nurses were found to work both directly and indirectly to mobilise services and resources for their clients (Howell, et al., 2008). With the direct strategy nurses refer clients to other services. The referral process necessitates identifying needs requiring further assistance, such as psychological issues (Victorian Centre for Nursing Practice Research, 2001). It also necessitates knowledge of the services available in the relevant area. Other professional and volunteer psychosocial support service options exist for women with breast cancer, though many areas are not able to access all possible resources. Often in rural areas, not all services are available, or are only available through fee paying public clients. As is intuitive, research has suggested the uptake of these services is related to the provision of information about them (Rankin et al., 2004). Rankin et al (2004) assessed referral uptake to the peer support program for women with breast cancer in Australia. In certain situations, facilitating access to services may require more than a referral and/or informing clients about services.

Another strategy which BNs can use is indirectly facilitating women's access to services through influence and creativity. Amir et al (2004) found BNs play an innovatory role in making the health system bureaucracy respond to clients' needs (Amir, et al., 2004). BNs were shown to find ways to 'work around the system' to enable women's needs to be met, often using their network of contacts to make things happen (Amir, et al., 2004). Studies appear to consistently reflect that BNs can enable continuity of care by "directly or indirectly influencing care for women with breast cancer at various phases in the patient journey, including diagnosis, treatment and follow-up, and in-patient and out-patient care" (NBCC 2005, p.11).

BNs may provide a 'map' for clients about the journey ahead, both empowering and informing women. Continuity of care is provided for the woman by supporting the woman's understanding of care processes, also called 'patient navigation'. Patient

navigation appears to be a major component of breast nursing, i.e. assisting women to negotiate the healthcare system, treatment choices, and the physical, emotional and practical challenges of their diagnosis, treatment and follow-up (Eicher, 2010). Studies report BNs assist women with practical information about what to expect (Halkett, et al., 2006). This has been captured in the literature as coordinating care, as well as referral, liaising, preparing women for and explaining the journey and healthcare providers along the way (SBN Project Team, 2000; Eicher, 2010). For instance, one study reported women consulting BNs as compared to those that do not, receive more information about supportive care options (Campbell, et al., 2006). This Australian study was based on an audit of a population-based sample of Australian women with breast cancer, however the data was collected in 1997.

Thus BNs can enable coordination and continuity of care for women. The literature highlights a number of ways this can be achieved. BNs can work as a key instigator of information sharing as part of the multi-professional team. BNs can facilitate women's access to services by appropriately referring women, as well as asserting her influence and creativity within the health system when necessary to ensure women are able to access the services they need. Additionally, BNs can provide women with navigation for the way forward which improves their understanding of care processes.

#### **2.3.2.4. Clinical Care**

Some BN services include components of physical clinical care (NBCC 2005; SBN Project Team 2000). It has been noted that the physical clinical involvement of BNs is dependent on the setting, and is more common in dedicated BN positions (NBCC 2005). Clinical care is a distinct core dimension of breast nursing, even though it usually only constitutes a small part of practice. This clinical care has been reported to include draining of seromas, wound assessment and dressing, and removal of sutures or drainage tubes, and the fitting of prosthesis in some clinical settings (SBN Project Team 2000; Victorian Centre for Nursing Practice Research, 2001).



In summary, breast nursing can bring about positive outcomes through information provision, support, coordination and navigation, and clinical care. BNs can provide high quality, relevant and timely information in line with women's needs and preferences. BNs can support women by creating a safe environment to share feelings and concerns whilst empowering clients in their journey. They can facilitate coordination of services through referrals and liaising with other health professional in formal and informal ways, while navigating the way for women. In some settings, BNs undertake discrete physical care relevant to breast cancer.

### **2.3.3. Potential Beneficial Outcomes of Breast Nursing**

The value of breast nursing services can be demonstrated by defining and measuring the positive consequences associated with breast nursing practices. Research has confirmed positive results arising from breast nursing practices for their clients and the treatment team who share the care of these women. This section reviews how breast nursing is substantiated by the evidence in the literature.

Overall, the potential beneficial outcomes of breast nursing practices care fall into four broad categories: psychosocial, physical, care continuity and satisfaction with care. Health professionals can benefit from better use of their time, better communication within the team, and better referrals. The purported beneficial outcomes reoccurring in the literature are summarised below:

- **improved continuity of care**, including women's understandings of care processes (Clacey, et al., 1988; Liebert, et al., 2003; McArdle, et al., 1996; Watson, 1988);
- **decreased psychological morbidity**, including distress and anxiety (Maguire, et al., 1983; McArdle, et al., 1996; Watson, 1988);
- **women received more information** relevant to the breast cancer experience (SBN Project Team, 2000; Campbell, et al., 2006; Liebert, et al., 2003);

- **improved women's knowledge and recall** of information (Clacey, et al., 1988; Devine & Westlake, 1995);
- **increased women's understanding** of breast cancer diagnosis, treatment options, and the team members involved in their care (Clacey, et al., 1988; SBN Project Team 2000);
- **increased women's perceptions of support and satisfaction with care** (Campbell, et al., 2006; Garvican et al., 1998; Koinberg, et al., 2004; Liebert & Furber, 2004; SBN Project Team 2000; Szwajcer, et al., 2004);
- **the presence of a BN would affect women's choice of treatment centre**, and what they would recommend to others (Eley, et al., 2008; Liebert, et al., 2003)
- **improved early detection of psychological morbidity** (SBN Project Team, 2000; Maguire, et al., 1980);
- **improved referral for psychological morbidity** (Maguire, et al., 1980)<sup>9</sup>
- **reduced severity of physical symptoms** (Devine & Westlake, 1995; Meyer & Mark, 1995);
- **more appropriate referrals and use of time for health professionals** (Liebert, et al., 2003; SBN Project Team 2000); and
- **resource or expert for health professionals** to draw upon (Carnwell & Baker, 2003a).

### 2.3.3.1. Benefits for Women

In combination, the research provides strong evidence for the potential beneficial outcomes of breast nursing for women. This does not mean all clients necessarily will receive these outcomes, instead these outcomes were demonstrated in one or more studies involving breast nurses - or interventions which can be used by BNs. The benefits women can receive by consulting a BN are summarised and collapsed below into the aforementioned categories (i.e. psychosocial, physical, care continuity and satisfaction with care).

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<sup>9</sup> However, referral for psychological morbidity has received mixed results, as discussed later.

A multitude of psychosocial benefits for women can result from breast nursing. Women consulting BNs can receive improved information and support as compared to those that do not consult with BNs (Campbell, et al., 2006; Liebert, et al., 2003; SBN Project Team 2000; Williams et al., 2002). Results demonstrate women's breast cancer knowledge and recall rates are higher when women receive the type of psycho-educational care BNs can provide (NHMRC NBCC Clacey, et al., 1988; Devine & Westlake, 1995; 1999). Breast nursing interventions can also result in their clients experiencing better psychological status, with lower incidences of psychological morbidity among women consulting BNs e.g. most notably reductions in psychological distress (SBN Project Team, 2000; Devine & Westlake, 1995; McArdle, et al., 1996; Watson, 1988). However, the experience of breast cancer remains psychologically challenging for many, and psychological morbidity can still be high for women with regular BN involvement (Clark et al., 2009; Parle, et al., 2001; SBN Project Team 2000). Yet, BNs reportedly have the capacity and skill to identify psychological morbidity and appropriately refer women (Maguire, et al., 1983; Maguire, et al., 1980)<sup>10</sup>. Overall, women consulting BNs (or receiving interventions BNs can provide) have reported improved quality of life (Badger et al., 2005; Meyer & Mark, 1995; Ritz, et al., 2000).

BN interventions can diminish some physical symptoms (e.g. nausea, pain, and vomiting), though perhaps not others (e.g. arm swelling and disability). Meta-analysis' have confirmed psychological interventions for adults with cancer, like those provided by BNs, can reduce the severity of physical symptoms (Devine, 2003;

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<sup>10</sup> Results are mixed as to whether this early detection leads to referral to specialist psychological services. While earlier UK studies found this to be the case (see for example: Maguire, et al., 1983; Maguire, et al., 1980), the findings of an Australian study conflict with these results. Although BNs were detecting psychological morbidity in their clients, referrals to psychological services were few (Parle, et al., 2001). The authors suggested this was due to BNs experiencing barriers to referral, such as the lack of specialist mental health services.

Devine & Westlake, 1995). Specifically, psycho-educational care improves nausea, pain, and vomiting. Yet, some studies have found breast nursing care did not significantly impact physical symptoms, such as arm swelling and disability (for example see: Maguire, et al., 1983).

Breast nursing has consistently led to high levels of satisfaction with care amongst their clients. In particular, BN clients regularly report being satisfied with BN care (Garvican, et al., 1998; Koinberg, et al., 2004; Liebert & Furber, 2004; SBN Project Team 2000). Specifically, women report being satisfied with how they received support from BNs (Campbell, et al., 2006), and perceived they benefited from the nurses involvement in their care (Liebert & Furber, 2004; Szwajcer, et al., 2004). Overall, women typically value BN services and report these services positively impacted their cancer experience (Carnwell & Baker, 2003c). This is particularly true for rural women who often experience a sense of isolation with the added distance between themselves and their families during treatment (SBN Project Team 2000). Consequently, most women say the presence of a BN would affect their choice of a treatment centre, and their recommendations to friends and others (Eley, et al., 2008; Liebert, et al., 2003; SBN Project Team 2000).

Breast nursing can also lead to improved continuity of care for women diagnosed with breast cancer (Liebert, et al., 2003; McArdle, et al., 1996; SBN Project Team 2000; Watson, 1988). When nurses liaise with and refer to other team members and services, and facilitate information exchange, women's care has more continuity (Howell, et al., 2008). For example, women are referred more appropriately when a BN is involved in their care (Liebert, et al., 2003). Furthermore, women understand the general care processes, or what is happening next, which results in decreased anxiety (Halkett, et al., 2006; McArdle, et al., 1996).

Significantly, the benefits to clients of specialist prostate cancer nurses are found to be consistent with those of BN clients. Namely, a large mixed methods study identified more positive experiences of written information provision, participation in decision making, and knowledge of support available were reported by their

clients than men who did not have access to prostate cancer nurses (Tarrant, et al., 2008).

### **2.3.3.2. Benefits for Health Professionals**

Health professionals sharing the care of women with breast cancer report the BNs inclusion in the team bring about beneficial outcomes for them too. BN involvement can enable more appropriate use of time for the other members of the treatment team along with more appropriate referrals (Liebert, et al., 2003; SBN Project Team 2000). The BN can also improve communication:

“SBNs are highly valued within treatment teams ... precisely because of their ability to move between members of the team, and between women ... and the team. Such movement, which often takes place across different physical locations, is valued as an information sharing system ...” (SBN Project Team 2000, p.35).

The inclusion of a psychosocial role in the cancer care team is reportedly appreciated by many specialists and nurses (Sellers, 2000; SBN Project Team, 2000). “Anecdotally, physicians mentioned how their load seemed lighter or they were free to take on more patients because of this service” (Sellers, 2000, p.29). Furthermore, the BN has been considered a valuable resource for other health professionals (Carnwell & Baker, 2003a).

In conclusion, women can benefit in a multitude of ways from breast nursing practices, and health professionals may also benefit. The beneficial outcomes of breast nursing for women can include psychosocial, physical, satisfaction with care, and continuity of care. Health professionals can also benefit from the improved continuity of women’s care in that their time is used more appropriately, communication is improved, and the BN can be a valuable resource for them.

#### **2.3.4. Critical Analysis of the Breast Nursing Literature**

A strong research base has driven interest in and credibility for breast nursing by helping to substantiate the BNs' existence and interventions. This is in spite of BN care and outcomes being challenging to measure and quantify. The evolving nature of the BN role has made breast nursing outcomes difficult to capture, while changes in breast cancer treatments and healthcare services only complicate the matter (RCN 2004). Furthermore, the breast nursing research to date has been limited by an inability to capture comprehensive care nor complexity of practice. An overview of the seminal works, the range of research published, and gaps in the literature are described below.

The BN literature to date has largely focused on two areas: specific breast nursing practices and their specific effects for women, and general assessments of satisfaction with care and/or usefulness of BNs. Essentially, the research has shed light on a multitude of breast nursing practices demonstrating beneficial outcomes for women. In addition, the research has consistently shown women value breast nursing care, and women and health professionals alike are satisfied with the care BNs provide.

BN scientific literature while informative, is skewed toward best practice research environments. As highlighted in Chapter One, few studies have explored real world practice, especially outside of metropolitan settings (for exception see: Eley, et al., 2008; and Howell, et al., 2008). Furthermore, the vast majority of models and/or descriptions of practice in the scientific literature are from hospital settings or cancer clinics, with few exceptions (for exception see: Eley, et al., 2008; and Howell, et al., 2008). The accounts describing real world practice of BNs in Australia, the UK, and elsewhere are largely limited to the grey literature. Although the grey literature more fully describes breast nursing practices, it can be difficult to assess the quality of the results presented.

BN research has generally focused on evaluating individual breast nursing interventions, with few comprehensive evaluations or descriptions of BN practice (iSource NBCC 2003). Although a few obvious exceptions exist (such as: SBN Project Team 2000), breast nursing descriptions are typically limited to one aspect of care, phase of care, and/or setting. Intervention studies have focussed on one aspect of care, such as coping with radiation therapy (Wengström, et al., 2001), rather than the full spectrum of care, which can be much more complex to evaluate.

Indeed, the general nursing literature identifies challenges in evaluating complex healthcare interventions and their outcomes. Blackwood et al (2006) described methodological issues and distinct challenges in evaluating complex healthcare interventions (Blackwood, 2006). Corner et al (2003) highlighted the challenges in identifying the outcomes of specialist nursing care, especially as their interventions are often complementary to the work undertaken by other health care providers (Corner et al., 2003). Furthermore, the wider nursing literature recognises that factors other than nursing interventions impact nursing and client outcomes. For instance, nursing and client outcomes are influenced by organisations, nurses' educational preparation and personal skills (e.g. emotional intelligence) (Bulmer Smith et al., 2009; Woodward et al., 2005, 2006).

When aspects of breast nursing practices are described in the literature, the descriptions are brief. For example, the psychological support provided by one nurse at the first visit peri-operatively was detailed by McArdle et al (1996) in four paragraphs, which did not include important information such as the usual number of contacts or their duration. Moreover, when systemic care is described, often client satisfaction is the only outcome measure used. For example, if women found it helpful to speak with the BCN (Szwajcer, et al., 2004). However, a few studies provide a more comprehensive picture of the scope of nursing practices (see for example: Howell, et al., 2008; and SBN Project Team 2000). Comprehensive mixed method descriptive studies appear to be especially informative in guiding cancer

nursing supportive care models (for example see: Howell, et al., 2008; Ream, et al., 2009).

The literature is sparse with regard to the complexity of breast nursing practices. This is especially true for explanations of how the specific nurse undertaking the role and the setting within which the BN is placed impact breast nursing practices and outcomes. Although a nuanced description of breast nursing practices in the UK was provided by Tait (1995), many of the important themes she raised have not been pursued with further published research (e.g. considering how the work setting and BN personality impact practice). However, grey literature has been identified that has considered what factors influence breast nursing practices (see for example (Victorian Centre for Nursing Practice Research, 2001)).

In summary, the research has built the foundations for breast nursing by detailing specific interventions demonstrated to be effective, and providing evidence of satisfaction with care and the perceived value from women. More recent work from Australia and Scandinavia has built on seminal UK research. However, comprehensive assessments exploring the complexities of the many elements influencing real world nursing practices and outcomes have not been undertaken. The implications of the limitations of the research to date are discussed further in the next section.

## **2.4. Rationale for Study Approach**

Throughout this chapter and the introduction, gaps in the breast nursing literature have been highlighted. This section synthesizes and summarises the major gaps identified in the literature pertaining to breast nursing. Outstanding questions remain around what BNs' do. The research base needs to be improved with results which can more practically assist in planning health service delivery by providing information which is readily useful to inform practice (Redman, et al., 2003). The need for comprehensive assessments, consideration of care contexts and care providers, detailed practice descriptions, more information on practical intervention



aspects and effectiveness in real world practice, and specific insights to inform rural practice are discussed below.

### **Comprehensive Assessments of Systems of Care**

Cancer care needs to be assessed as part of a system of care, using a broad outcome assessment measure. Ultimately, cancer care is a system (Verhoef, et al., 2007). The many components of care interact with each other, regardless of whether they are formally connected or not (Verhoef, et al., 2007). Breast nursing practices are inevitably affected by those health professionals who share the care of the client. This “recognition of the critical interdependence between the SBN role and other nurses and health professionals involved in a woman’s care” is particularly relevant to the ‘collaborative care’ domain of practice (Yates, et al., 2007, p.13). Furthermore, other care providers and the health system generally also impact the outcomes received for women. Thus, it is important to conceptualise and evaluate the package of care that client’s receive (Verhoef, et al., 2007). Beneficial insights could be gained by understanding how BN services fit within the local care system(s). A holistic outcome measure is then better able to determine if the cancer care system, with the support of the BN, is resulting in the desired supportive care outcomes.

Comprehensive assessments of systems of care are the ideal way to evaluate the system. A systemic mixed methods approach more fully defines and evaluates breast nursing practices than studies that focus on single aspects of care. In order to fully encapsulate an evaluation of cancer care, a systemic approach benefits from a program of studies and a mixture of quantitative and qualitative methods to capture the complexities of real world practice (Verhoef, et al., 2007). “(E)valuative methods must address the synergistic and flexible nature of individualized cancer care and therefore go beyond traditional randomized controlled trials (RCT), which are currently considered the gold standard for testing medical interventions” (Verhoef, et al., 2007, p.906).

Systemic evaluations of breast nursing practices, using quantitative and qualitative inquiry to build on one another, have been limited. The NBCC SBN Demonstration Project is an obvious exception, along with the studies of the North Wales BN services (Carnwell & Baker, 2003a; Carnwell & Baker, 2003b; Carnwell & Baker, 2003c). When qualitative work has been combined with quantitative research, it has generally been to report client satisfaction and/or describing what BNs do from the client or BN point of view. Important insights could be gained by asking BNs why they do what they do.

Comprehensive Australian studies of BN services have been limited to the NBCC's Demonstration Project. Otherwise, Australian BN descriptions and assessments have been limited to one nurse (Eley, et al., 2008; Szwajcer, et al., 2004); women's experiences of BN without a clear picture of the care protocol of the various nursing roles (Campbell, et al., 2006; Halkett, et al., 2006); and/or restricted to analyzing the care during only one phase, such as follow-up (Jiwa, et al., 2010).

### **Care in Context**

Considered descriptions of how settings have impacted breast nursing practices will benefit efforts to maximise BN effectiveness in real world practice. As the model of care must fit within the local context, it is important to describe the context along with the actual model of care. When researchers call for more uniform models of care, they often fail to acknowledge the importance of roles fitting within the context, and that the context can in turn influence outcomes. Specifically, "health service planners need information about ... how programs might operate in the context of their systems" (Redman, et al., 2003, p.522).

How breast nursing practices are influenced or shaped by their context is missing from the literature. How the BN service links with the context or setting can greatly impact outcomes and processes. Yet, the interface between model of care and context is generally only briefly mentioned, if at all, in the scientific literature. The description of a model of care is said to include "the delivery of health care within

the broader context of the health system” (Davidson, et al., 2006, p.49). It is this link between the model of care and the wider healthcare context which receives scant attention from the literature on breast nursing. Whether it is simply taken for granted, not reported, and/or not considered is not known. The wider context can have major implications on the model of care, regardless if one is attempting implement the same core evidence base into clinical practice.

Furthermore, research on rural BN practices has been conspicuous by its absence. Efforts to implement effective rural BN services would benefit from a greater diversity of descriptions and assessments of rural breast nursing practices, including more nurses and sites. Only two descriptions and/or assessments of Australian rural BN services are available in the scientific literature. Other than the rural site within the NBCC SBN Demonstration Project, one other research report details a rural or regional BN service (Eley, et al., 2008; Liebert, et al., 2003). This was an evaluation of one full-time BCN implemented in a local health service in regional Queensland, Australia<sup>11</sup>. However, both descriptions were limited to one nurse at one rural site, which limit the transferability of the findings.

### **The person who embodies/undertakes the BN role**

Little consideration has been given to the effects of the personal and professional aspects of the nurse on breast nursing practices and client outcomes. Australian studies have alluded to the personal attributes of the incumbent contributing to positive client outcomes, but this has not been studied *per se* (Eley, et al., 2008). If

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<sup>11</sup> The Queensland BCN worked from a large rural centre, Toowoomba, with good access to health services (Eley, et al., 2008). The BCN serviced areas which included Toowoomba, less accessible small rural areas and outer regional areas, as well as poorly accessible remote and very remote areas (RRMA 3 to 7). About half of her clients had their first contact at or around diagnosis, with >90% consulting with her pre surgery. As per their BCN protocol, all clients had at least 5 scheduled contacts with the BCN, which coincided with other hospital treatment or assessment visits. Clients were invited to seek additional contacts, with those living further away more likely using the telephone, and those living closer to the hospital using face-to-face.

individual nurse attributes influence breast nursing practices and outcomes, these insights can assist those designing and hiring for BN services.

### **Detailed Practice Descriptions**

Research is needed that describes breast nursing practices in terms of the dose received for clients to assist understandings of BN contributions. Care protocol information is typically limited; making it difficult to assess what was actually delivered. There is a severe lack of evidence-based advanced BN practice descriptions (Amir, et al., 2004). Often not enough detail is provided in the literature to assemble a picture of the full breast nursing practices. Research instead tends to focus on one intervention or component of care. The reader can be left wondering about the dose of the intervention and the most central aspects of the intervention content (Stanton, 2005).

‘Dose’ measurements are important in understanding a nurse’s contribution to patient care and outcomes (Manojlovich & Sidani, 2008), but rarely reported in relation to breast nursing. The concept of dose contains four parameters: what (i.e. purity), how much (i.e. amount), how often (i.e. frequency), and how long (i.e. duration of care) (Manojlovich & Sidani, 2008). It is challenging to understand breast nursing practices without a published account of what happens such as the "number of sessions attended, total contact time, and primary content of the individually tailored intervention" (Stanton, 2005, p.4819).

### **Practical Aspects – case loads & telephone support**

Research needs to include practical aspects about BN services to enable health service planners to determine appropriate staffing arrangements. A limited amount of information exists about practical aspects of breast nursing practices, specifically caseloads and the use of telephone support. Others have similarly called for more research in these areas to inform effective practice (Marsh, et al., 2010; SBN Project Team 2000). Research has often failed to report patient loads, although the NBCC SBN Demonstration Project reported a wide range of client loads. Reports on

caseloads in various contexts could inform health service managers to plan for appropriate nursing hours.

Telephone consultations have been recommended as a means for nurses to support patients. A combination of home and telephone contacts is suggested as a cost-effective option for providing informational support to patients by nurse (Hughes, et al., 2000). A literature review of nurse-led telephone follow-up in cancer care demonstrates it meets clients' needs for psychological support and information (Cox & Wilson, 2003). Moreover, telephone counselling has been recommended as a means to support rural Australian women with breast cancer (Davis, et al., 2003). Although nurse-led telephone support for people with breast cancer appears to be a viable delivery modality (Sandgren & McCaul, 2007), its use has received little attention in the context of breast nursing practices.

More research on breast nursing practices and outcomes using combinations of face-to-face and telephone support would inform effective services, particularly in rural areas. There is little research about the use of telephone support by BNs. The use of telephone and face-to-face consultations is apparently varied and often undescribed in the literature. In the NBCC SBN Demonstration Project, telephones were used minimally for diagnosis, pre and post-operative consultations, and first follow-up, while about a quarter of second follow-up consultations were conducted over the telephone (all <5%, 9%, and 28% respectively) (SBN Project Team 2000). In a randomised evidence trial, telephone follow-up by SBNs resulted in reductions of levels of anxiety, detection time of recurrent disease, and clinical investigations ordered equivalent to standard hospital physician-led follow-up, yet with significantly higher levels of satisfaction with the nurse (Beaver et al., 2009).

### **Effectiveness in Real World Practice**

Research is needed that explores the effectiveness of breast nursing practices under 'real world' conditions. An important distinction exists between efficaciousness and effectiveness (Chambless & Hollon, 1998). Namely, interventions may be

efficacious under controlled conditions (i.e. treatments yield desirable results), yet the interventions ability to yield desirable results under real world circumstances in practice has been more difficult to establish. BN research to date has focussed on interventions under ideal trial conditions. More evaluations of the effectiveness of supportive care programs implemented in real world conditions are needed (Redman, et al., 2003; Szwajcer, et al., 2004). "It will be necessary to focus at the population level on modifying services and policy and to consider the effectiveness of programs in practice rather than just their efficacy under trial conditions" (Redman, et al., 2003, p.522). The effectiveness of breast nursing practices remains a central question, particularly in rural areas. Furthermore, informing rural breast nursing practices may be even more important as rural nurses often have little collegial support in defining appropriate nursing practices(Long & Weinert, 2010).

Therefore, there are major gaps in knowledge around how BNs undertake the role in real world practice, particularly in rural areas. There is no comprehensive systemic description of rural breast nursing practices. Limited information exists about breast nursing practices in rural as compared to urban areas, and if there are differences based on contextual features. Furthermore, there is limited knowledge about caseloads and the use of telephone consultations. Sparse information exists about how BN services are influenced by settings, and how they fit within the total breast cancer care package. Additionally, details on the effectiveness of breast nursing services under real world conditions are scant. Thus, rural breast nursing practices are an understudied entity that, with further research, can improve services and benefit women with breast cancer. These gaps are further compounded as there has generally been a lack of application of theory to the supportive cancer nursing literature, with few exceptions (for example: Howell, et al., 2008). Gaps in the literature leave questions around breast nursing practices in rural settings.

## 2.5. Conclusion - a Gap in Understanding

This literature review has identified major gaps in knowledge around breast nursing practices, particularly in rural areas. Specifically, limited research addresses what happens in real world practice, the influences on nursing practices, and the effectiveness of BN services. Clinical practice guidelines recommend SBN involvement in the care of women with breast cancer along with many supportive care interventions BNs can deliver. While this body of research provides insights into optimal breast nursing interventions and the positive outcomes for women that can result, scant research addresses effectiveness in real world practice. Additionally, little research informs the challenges in translating research best practice to real world breast nursing practices.

Extensive evidence exists around the specific interventions BNs can use and the benefits that can result from these interventions. Missing from the BN literature is a framework that considers the influences on breast nursing practices. Specifically, there is little BN literature that discusses the impacts of settings and/or the nurses themselves on breast nursing practices. These insights could better inform real world services.

There is also a dearth of literature exploring how BNs interface with their organisations and wider settings. Although the need for wide healthcare system support for BNs has been noted, how different levels and/or aspects of support influence breast nursing practices have not been explored. Instead, most breast nursing research has been undertaken in highly supportive environments which are atypical for BN services. This reliance on research from best practice settings, and dearth of knowledge about influences on nursing practices, makes translating evidence to practice challenging for service planners. Thus, this study aims *to advance knowledge of rural breast nurses' practice within real world contexts*.

Combining quantitative and qualitative inquiry has been limited in the BN literature. The use of qualitative and quantitative descriptions of nursing practices in

combination with qualitative inquiry to understand the influences on breast nursing practices can be informative. Instead qualitative tools have often been limited to assessments of patient satisfaction. No qualitative work has been done on *why* BNs do what they do.

Furthermore, there is little information on the rural practice reality. It appears models previously considered acceptable and transferrable were in fact not sustainable. Thus, the use of a research approach which describes *what* breast nursing practices are like in rural settings and explores *why* breast nursing practices happen as they do can certainly advance knowledge. Additionally, the use of broad outcome measure acknowledges the complimentary nature of the BN role along with the important question of real world effectiveness.

Therefore, this study focuses on identifying actual breast nursing practices in rural settings, the influences on these nursing practices, and the outcomes of their clients.



# Chapter Three: Methodology

Chapter One identified the rationale for the aim and the research questions of this thesis while Chapter Two provided the rationale for the study approach. This chapter describes the research methodology used in this study. It presents the philosophical perspective within which research decisions were made. Sections describe the pragmatic paradigm and conceptual framework within which the research is placed.

The research questions and methods are framed within a pragmatic philosophical perspective. “By pragmatism, we mean to search for workable solutions through the practice of research (e.g., follow the fundamental principle of mixed research, including the use of designs and criteria that are situation and context appropriate) to help answer questions that we value and to provide workable improvements in our world (i.e., help in bringing about desired outcomes)” (Onwuegbuzie & Johnson, 2006, p.54). The pragmatic philosophical perspective within which this thesis is placed is described below.

## 3.1. Philosophical Perspective

This thesis is placed within a pragmatic theoretical perspective using an intervention theory conceptual framework. The research questions are informed by the pragmatic perspective, as are the data collection and analysis. The pragmatic theoretical framework fitted within this study’s aim *to advance knowledge of rural breast nurses’ practice within real world contexts*. This research is primarily descriptive and hypothesis generating, rather than aiming for statistical significance. The thesis constitutes interdisciplinary applied research in the naturalistic setting.

Quantitative and qualitative inquiry was used to understand what RBNs do and their client’s supportive care outcomes, as well as what factors impact how RBNs go

about breast nursing. This thesis rejects the incompatibility hypothesis, which contends that quantitative and qualitative research paradigms and methods cannot be combined in a useful way (Teddle & Tashakkori, 2009). The traditional dualisms of qualitative and quantitative purists' approaches limit the scope of inquiry and utility of findings. Instead, this research is based on the pragmatist assumption that forms a fundamental principle in mixed research: that collecting diverse types of data best provides an answer to the question (Johnson & Turner, 2003). In this case, the question is how to undertake rural breast nursing practices to meet the supportive care needs of women with breast cancer.

Philosophical perspectives can be placed on an epistemological continuum, although the purists' perspectives have historically been conceived of as 'at war' or in a debate and thus dichotomised. Pragmatism essentially sits in the middle of a philosophical continuum ranging from positivism to constructivism (Onwuegbuzie et al., 2009). The ends of the philosophical continuum approach the research process with different beliefs and values and therefore use different methods to reach conclusions. Pragmatism's associated mixed methods similarly fall near the middle of a methods continuum ranging from quantitative to qualitative. Positivist philosophies utilise deductive logic and numbers to ascertain certainty. In contrast, constructivism and constructivist philosophies utilise inductive logic and narratives or textual data to gain meaning and understandings. Different questions are asked across the philosophical continuum – with qualitative research generally aiming to explore the world, and quantitative research typically aiming to test theory. While some researchers with different philosophical approaches may not see benefit in alternative approaches and find combining methods unviable, pragmatists instead see the usefulness in both quantitative and qualitative methods and furthermore in combining them. The pragmatic philosophy supports the utilisation of different combinations of quantitative and qualitative methods in order to best answer research questions (Onwuegbuzie, et al., 2009).

The philosophical underpinnings of this research project – from research questions to methods, analysis, and conclusions – are shaped by the pragmatic philosophical framework. The philosophical approach of pragmatism rests neatly with the principles of mixed methods research, and has been identified as a solid paradigmatic underpinning for this mixed methods approach to solving problems (Johnson & Onwuegbuzie, 2004; Onwuegbuzie, et al., 2009; Teddlie & Tashakkori, 2009).

### **3.1.1. Pragmatism**

Pragmatism arose as its own distinct methodological orientation around 1990 (Teddlie & Tashakkori, 2009). Instrumental to the rise of pragmatism was the growth in popularity and refinement of qualitative methods, and the acceptance of triangulation methods (Teddlie & Tashakkori, 2009). Criticism of the incompatibility thesis prior to that time from various fields also helped to lay the foundation for pragmatism, for example in education (Howe, 1988). Seminal works in pragmatism arose in sociology and nursing fields: Brewer and Hunter's book was published in 1989 (Brewer & Hunter, 1989) and Morse wrote in 1991 in the Nursing Research journal about methodological triangulation (Morse, 1991). Both works discussed combining both qualitative and quantitative methods within one project, yet initial work on mixed methods kept the two purists' methods distinctly separate. The fundamental principle of mixed method research is that by combining quantitative and qualitative methods, the research conclusions benefits from complementary strengths and non-overlapping weaknesses (Brewer & Hunter, 1989).

This study reflects the existence and importance of physical and social realities in pragmatism (Johnson & Onwuegbuzie, 2004) through the collection of relatively objective facts (e.g. surveys and logs) and individual's thoughts and understandings (e.g. interviews). Pragmatists believe in an objective physical reality and place importance on subjective realities formed within individuals' minds. The ontological belief is of multiple realities with a "high regard for the reality and influence of the inner world of human experience in action" (Onwuegbuzie, et al., 2009, p.122).

Thus, it is understood there can be a physical reality along with mental and/or social realities, perspectives, or beliefs. Furthermore, current truth and knowledge are considered tentative and changing.

The knowledge constructed within this thesis (i.e. nature of knowledge or epistemology) is built from objective and subjective learnings, relying on the experiences and perspectives of RBNs and the women consulting them. Relatively objective information was sought in logs, whereas experiences were sought in interviews, and sense-making was deemed to be more complete with the combination of the multiple means to access knowledge. From the pragmatic perspective, knowledge is both socially and/or personally constructed and based on a physical reality that we experience (Johnson & Onwuegbuzie, 2004). Knowledge is considered intersubjective, meaning each individual has their own slant on truth (Onwuegbuzie, et al., 2009). "Knowledge is both constructed and based on the reality of the world we experience and live in" (Onwuegbuzie, et al., 2009, p.122). Knowledge can be gained through multiple ways of knowing, utilising inductive and deductive logic, as utilised in this thesis.

#### **3.1.1.1. Guiding Features of Pragmatism**

Beyond the underlying ontology and epistemology foundations, there are other characteristics of pragmatism which are consistent with this thesis. Key guiding features of pragmatism are described in this section. Pragmatic research typically:

- builds on previous research and knowledge,
- recognizes the research process is inherently value-laden,
- uses the research questions to drive method selection,
- seeks practical answers to inform effective real world practice, and
- acknowledges the influence of context on the research process and findings.

This thesis is grounded on previous knowledge and experiences (of the researcher, and others) and aims to add depth of understanding to improve practice, consistent with the ongoing inductive-deductive research cycle of pragmatism (Teddle &

Tashakkori, 2009). Knowledge is accumulated in a dynamic process which “constantly tries to improve upon past understandings in a way that fits and works in the world in which he or she operates” (Johnson & Onwuegbuzie, 2004, p.18). This infinite loop of learning continues to better itself and adapt to new situations and changing physical and social realities.

The meeting of women’s supportive care needs through quality care are explicitly valued in this thesis in an effort to support women to have the best possible breast cancer journey. The value of meeting supportive care needs is demonstrated by unmet needs being selected as an outcome measure. The researcher decided what she wanted to study based on her value systems and the existing literature. Pragmatism recognises that the research process is inherently value-laden and places importance on this being transparent (Johnson & Onwuegbuzie, 2004). Values are also especially important in interpreting the results (Teddle & Tashakkori, 2009).

The research questions have driven the appropriate use of methods. The research questions of this study require simultaneous confirmation of theory, and exploration of explanations, as is consistent with pragmatic inquiries (Teddle & Tashakkori, 2009). The ‘best’ research methods (including data collection and analysis) are considered to be those that fit the research question and purposes. Data is collected in whichever ways are deemed best to understand the research problem and importantly provide practical solutions. Pragmatism “is eclectic, ... referring to the inclusion of multiple quantitative and qualitative techniques in one’s briefcase and then selecting combinations of assumptions, methods, and designs that best fit one’s research questions of interest” (Onwuegbuzie & Johnson, 2006, p.54). Importantly, the answers to these practical questions are intended to be useful to inform practice and policy – as well as theory.

As is typical of research grounded in pragmatism, this thesis is practically oriented in a naturalistic setting with a non-experimental design (Teddle & Tashakkori, 2009). As stated earlier, this thesis aims *to advance knowledge of rural breast nurses’*

*practice within real world contexts*. Thus it should inform practice through improved understandings of naturalistic breast nursing in rural settings – essentially aiming to generate knowledge that has practical implications. The questions of pragmatism are typically problem-centred, based on a real world situation which is deemed to be important. Pragmatism is real world practice oriented theoretical perspective (Creswell, 2003), with a focus on identifying solutions to real world problems that can work in practice. Research methods are utilised which will result in greater understanding the problems and identify practical workable solutions to inform effective practice (Johnson & Onwuegbuzie, 2004). This allows the researcher to “draw liberally from both quantitative and qualitative assumptions when they engage in their research” (Creswell, 2003, p.12).

The researcher pursued the collection of contextual information (e.g. personal physical observations and participants’ socio-cultural experiences) having witnessed the varied impacts of diverse settings on breast nursing practices. Context has often been identified as impacting discrepancies in findings of effectiveness (Teddlie & Tashakkori, 2009), and thus is recognised as important in this inquiry. It is acknowledged that contextually distinct experiences are common. The pragmatic perspective recognises the influence of the context – social, political, historical, etc – on the framing and outcomes of the research process (Creswell, 2003).

### **3.1.1.2. Rationale for Mixed Methods in Pragmatism**

The methodology provides a framework directing how research should proceed. “Methodology... is the analysis of how research should or does proceed. It includes discussions of how theories are generated and tested - what kind of logic is used, what criteria they have to satisfy, what theories look like and how particular theoretical perspectives can be related to particular research problems” (Blaikie, 1993, p.7). A mixed methods methodology falls neatly from a pragmatic research paradigm. A pragmatic perspective supports using an eclectic mix of methods and perspectives based on what is deemed to best suit each particular question or

problem (Onwuegbuzie, et al., 2009). The question is central to determining the methods.

Neither quantitative nor qualitative methods alone could answer the research questions, thus this formed the rationale for pursuing mixed methods research. Mixed methods provided the ability to confirm theory (i.e. the generic nursing conceptual intervention framework) and explore further details, as well as making stronger inferences (Teddlie & Tashakkori, 2009). Furthermore, combining quantitative and qualitative research methods enabled the researcher to attain information regarding individual/interpersonal and procedural/structural issues, and additionally to provide grounded and rich descriptions and explanations.

In this study, the mixing of methods supports the multiple aims of the study – for developmental, complimentary, and expansion purposes. The quantitative analysis results were used to inform the qualitative data collection topics, thus supporting the development of the qualitative phase. The qualitative inquiry served to enhance the understandings of rural breast nursing practices developed through quantitative inquiry, supporting the complementary goals of the study. Furthermore, the qualitative inquiry served to expand the quantitative learnings by addressing questions beyond the reach of quantitative inquiry.

The researcher found it natural to combine the methods of quantitative and qualitative inquiry, contending that a mix of inductive and deductive reasoning is a regular part of human inquiry. This idea is not new, with the early philosopher Kant highlighting that “the categories of qualitative and quantitative are necessarily part of human thought and the conclusions we construct about entities that are important to us” (Onwuegbuzie, et al., 2009, p.132). Furthermore, it has become ever more apparent that previously separate paradigms (e.g. positivism and constructivism) are not as pure as once thought. For example, in selecting a research instrument the researcher shapes the research process and thus influences the research outcomes.

The utilisation of mixed methods purportedly increases the depth and validity of the learnings. It is believed that the understandings provided by qualitative inquiry add meaning to the quantitative results. The mixed methods approach is deemed beneficial for capturing insights which might be missed when using only one means of inquiry. It has been suggested that mixed methods research produces more complete knowledge to inform theory and practice by increasing the scope and comprehensiveness of the findings (Creswell & Plano Clark, 2007; Morse, 2003). “The goal of mixed methods research is not to replace either of these approaches but rather to draw from the strengths and minimise the weaknesses of both the single research studies and across studies” (Johnson & Onwuegbuzie, 2004, p.14-15).

The inclusion of both qualitative and quantitative measures strengthens the descriptive capacity of the research project. “Recognizing that all methods have limitations, researchers felt that biases inherent in any single method could neutralize or cancel the biases of the other methods” (Creswell, 2003, p.15). The combination of quantitative and qualitative methods can be a favourable way to study complicated phenomenon. The qualitative data provides further elaboration and depth to the quantitative data. Multiple methods has the potential to lead to greater depth and complexity of understandings.

A "multi-faceted quest for knowledge is appropriate in a social science" (Griffiths, 2003, p.164) and healthcare sciences more specifically. Qualitative methods can research the parts of what is happening different to what quantitative methods can reach, and is said to work well in health services mixed methods research (Pope & Mays, 1995). Qualitative inquiry can assist with studying and understanding processes and influences on behaviour, whereas quantitative inquiry can describe what is happening objectively.

Thus, the scope and comprehensiveness of the findings are increased by mixing quantitative and qualitative inquiry. The mixing of quantitative and qualitative results has been termed integration, and this has been considered an interpretation



of results (Creswell, 2003). Integration most commonly occurs at the data analysis and interpretation stages (Creswell et al., 2003). It is viewed as a meta-inference relying on the inferences drawn from both qualitative and quantitative results (Teddle & Tashakkori, 2009). Each strand of the research project is linked and connected, or integrated to inform meta-inferences that are theoretically consistent (Teddle & Tashakkori, 2009).

Therefore, integration is a mixed methods term “that denotes making meaningful conclusions on the basis of consistent or inconsistent results. The term incorporates linking, elaboration, completeness, contrast, comparison, and the like” (Teddle & Tashakkori, 2009, p.305). Agreement between the inferences of strands of research can increase confidence in findings, while differences and contradictions between inferences can provide complementary descriptions and/or elaborate on a phenomenon (Teddle & Tashakkori, 2009). Furthermore, it is important that inferences, and meta-inferences, are consistent with theoretical frameworks. That is, the conclusions for each strand, and after integrating strands, build upon existing theory (Teddle & Tashakkori, 2009).

### **3.1.1.3. Use and Acceptance of Mixed Methods Research**

Mixed methods research continues to expand in popularity and acceptance, as evidenced by the publication of the *Journal of Mixed Methods Research* in 2007, and other journals devoting special issues to mixed methods research (Teddle & Tashakkori, 2009). Additionally, mixed methods have received support and an exponential increase in usage in nursing and other health sciences. Mixed methods’ methodologies account for the complex nature of health and healthcare, and the aim for knowledge to inform decision making is consistent in mixed methods and applied disciplines. Specifically, the study of more client-focused healthcare delivery and transforming research to practice are areas which have benefited and grown from the use of mixed methods research (Forthofer, 2003, p.258).

The framing of health services research questions within a pragmatic mixed methods approach has increased in usage and acceptance internationally (Clark, 2010; O'Cathain et al., 2007). Additionally, mixed methods popularity has grown in nursing and health services research (Bazeley, 2009). Recently, a book was published by Australian editors about using mixed methods in nursing and health sciences research (Andrew & Halcomb, 2009). Researchers in the United Kingdom cited comprehensiveness as the main motivation for using mixed methods, noting an improved capacity to understand the complexities of healthcare systems and delivery as well as settings (O'Cathain, et al., 2007).

Furthermore, mixed methods have been used successfully to explore the cancer experience and to inform nursing practice. For example, mixed methods were useful to describe experiences and measure outcomes for individuals using complementary therapies alongside traditional cancer treatment (Seers et al., 2009). Another mixed method study led to a greater understanding of the management of pain to inform nursing practice (Carr, 2009). Additionally, the pragmatic perspective has been identified to closely align with the nursing bodies desire for research to inform practice (McCready, 2010). As “nursing care is, by definition, holistic, encompassing the physiological, physical, psychological, social, and spiritual aspects of health” (Sidani & Braden, 1998, p.62), mixed methods have the potential to provide more comprehensive understandings of breast nursing practices. Nonetheless, there are criticisms of pragmatism and the use of mixed methods.

#### **3.1.1.4. Criticisms and Challenges of Pragmatism and Mixed Methods**

Pragmatism has its weaknesses, as do all theoretical perspectives. An important weakness of this methodological approach is that it does not sit within more well established methodological backgrounds, e.g. positivism and constructivism. Because of this, it is viewed by some theorists as unacceptable ‘meaning making’. The challenges of integrating two forms of logic can be difficult for mixed method studies (Onwuegbuzie & Johnson, 2006). The utilisation of both objective and

subjective ways of knowing, and especially integrating these in the final synthesized results has been challenged by purists (Teddle & Tashakkori, 2009). As mixed methods research is relatively new, understandings of, evidence for, and the general support for this approach are still developing. Although supporters believe that the convergence of a mixed method approach can strengthen the research, other researchers believe the two methods cannot be brought together and/or cannot fit within one paradigm. That is, they hold a belief in the 'incompatibility thesis' that two paradigms cannot be mixed (e.g. the use of two methodologies weakens rather than strengthens results and/or two worldviews cannot be combined).

Theoretical criticism of the use of mixed methods centres around the 'incompatibility thesis', the belief that quantitative and qualitative methods cannot be combined given their differing perspectives and assumptions (Teddle & Tashakkori, 2009, p.98). Some suggest the dichotomy of the world views negates the possibility of combining methods. Some theorists purport that one person cannot hold more than one world view (Sale et al., 2002). Sale et al (2002) presented a more nuanced recommendation for when methods can (i.e. for complementary purposes) and cannot be mixed (i.e. cross-validation or triangulation).

Although the pragmatic research approach has been generally successful from a practical standpoint, some current philosophers consider that theorists of pragmatism have not adequately addressed philosophical disputes. "More theoretical, conceptual and practical work is needed in the area of mixed research" (Onwuegbuzie, et al., 2009, p.116). Most notably, the area of mixed methods integration is lacking in a generally accepted framework. Onwuegbuzie and Johnson (2006) explain that the complexity of combining quantitative and qualitative methods leads to problems of integration.

Earlier, Teddle and Tashakorri (2003) highlighted six challenges to mixed methods research: paradigm issues, rationale for use, design classifications, nomenclature

and definitions, making inferences and assessing their quality, and the logistics of mixed methods research. Presently, some of these issues still remain, namely:

- how to frame research questions in mixed methods studies (e.g. separate quantitative and qualitative questions, overarching mixed questions, or separate questions for each phase);
- how to integrate quantitative and qualitative research strands, and inferences;
- how to determine quality mixed methods research with the acceptance of consistent quality frameworks; and
- settling on consistent nomenclature, definitions, and taxonomies (Teddle & Tashakkori, 2009).

Mixed methods have also received criticism for practical reasons. Practically speaking, a new mixed methods researcher must ensure appropriate skills and expertise in both quantitative and qualitative data collection and analysis.

Considerable time and resources are required to complete the two separate phases in sequential studies in particular (Creswell, et al., 2003; Ivankova et al., 2006). Substantial skills and knowledge are needed for a researcher to undertake both qualitative and quantitative strands of research along with appropriate integration (Johnson & Onwuegbuzie, 2004).

Despite the criticisms and challenges of pragmatism and mixed methods, the researcher has reached the methodological assumption that quantitative and qualitative ways of knowing can be combined to better answer her research questions.

### **3.1.2. Judging the Quality of the Design and Interpretations**

All research approaches aim to provide high quality methods and results, and provide a means to assess this quality. Various paradigmatic approaches utilise different terminology to describe similar quality constructs. The nomenclature used by each approach represents similar but not identical constructs. Table 1 displays

the different yet similar terms to determine quality in research projects. Methodological approaches use different terms to refer to similar constructs of research quality.

Legitimation is a term used to describe the validity or trustworthiness of a mixed methods study (Onwuegbuzie & Johnson, 2006). Legitimation is essentially a process by which the quality of a study is determined. The evidence of quality in mixed research is in the results, i.e. if it produces useful results and adds to or builds useful theory (Onwuegbuzie & Johnson, 2006). However, steps can be taken to legitimise the inference quality through design quality (i.e. methodological rigour) and interpretive rigour (i.e. validity of conclusions), as well as the inference transferability (Teddle & Tashakkori, 2009). Onwuegbuzie and Johnson (2006) purported that to legitimate mixed methods research, each quantitative or qualitative strand is legitimated, as is the integration process of the different strands.

**Table 1: Terms to reflect constructs of research quality across various methodological approaches**

DESCRIPTOR	QUANTITATIVE	QUALITATIVE	MIXED METHODS
Quality – generally	Validity	Trustworthiness	Legitimation (Onwuegbuzie and Johnson 2006)
	Internal validity	Credibility	Inference quality = design quality and interpretive rigour (Teddle and Tashakkori 2009)
	External validity	transferability	Inference transferability

A few early frameworks for evaluating mixed methods studies have been put forward. A validation framework was proposed by Leech et al to assist researchers to evaluate mixed methods research (Leech et al., 2010). Leech et al (2010, p.21) stated that “the question of how to approach validity in mixed research continues to evolve.” Yet, the clearest framework for evaluating the quality of mixed methods research at this time is that proposed by Teddlie and Tashakorri (2009).

Teddlie and Tashakorri's integrative framework for inference quality and transferability was used to assess the quality of this mixed methods research (Teddlie & Tashakkori, 2009). Two components are important in assessing inference quality. "The quality of inferences depends on the quality of inputs to the process (i.e. design quality) and the integrity of the process of making meaning (i.e. interpretive rigor)" (Teddlie & Tashakkori, 2009, p.286).

### **3.1.3. Generic Nursing Conceptual Intervention Framework**

The use of a theory-driven conceptual framework for evaluating nursing interventions was introduced generally in Chapter One. It is described in detail here. This thesis employs and adapts the generic nursing conceptual intervention framework originally developed by Sidani and Braden (1998). Furthermore, a diagram was developed in this thesis to visually represent the generic nursing framework.

Sidani and Braden's (1998) intervention theory in effectiveness research asks that researchers and program designers build on what is known, or presumed to be the case, to formulate a framework for theory-driven intervention implementation and/or research. The problem the intervention is aiming to fix or improve is specified. The nature of the intervention (i.e. components and strength) is to be described, as are the processes through which the treatment is expected or known to work. The expected outcomes should be identified. Finally, the base requirements under which the intervention can be effective (i.e. extraneous features such as setting, client, and intervener characteristics) are to be described. From the identified problem, intervention, processes, outcomes, and required conditions, a theory-driven framework emerges. Features of the theory-driven intervention framework include key operating variables of intervention, process, outcomes, extraneous features, and the relationships between each (Sidani & Braden, 1998).

Sidani and Braden proposed a means to evaluate nursing interventions with the use of a theory-driven approach (Sidani & Braden, 1998). Importantly, the theory driven approach acknowledges that it is not only the intervention which affects outcomes. The context and client also impact outcomes, and these along with the intervener have the potential to influence the intervention delivered. “The basic premise in this approach is that outcome achievement is variable, and variability in outcomes can be explained by multiple factors inherent in the real world of everyday practice” (Sidani & Braden, 1998, p.61). The factors are grouped into five categories, namely patient characteristics, personal and professional characteristics of care-giving professionals, care setting physical and social features, intervention type and dose, and nature and timing of outcomes (Sidani et al., 2004).

The theory-driven approach purports that patient, intervener, intervention and context factors influence outcomes (Sidani & Braden, 1998). “Factors related to patients receiving care, to nurses providing care, to the setting or context in which care is provided, and to the nature of the care provided, interact and affect the outcomes expected as the result of care” (Sidani & Braden, 1998, p.60). The characteristics can have direct or indirect effects on outcome.

Patient characteristics, specifically their personal, health and resource characteristics, directly affect processes of care and outcomes received. Yet, “controlling for patient characteristics does not reflect the real world, where individual variability is the norm...” (Sidani & Braden, 1998, p.62). Thus patient characteristics must be considered and acknowledged in their impact on processes of care and outcomes in real world practice.

The personal and professional characteristics of the intervener also impact the care provided and outcomes received too. An intervener’s professional education and experiences can influence how she goes about her job, while her personal features and style can do the same, and impact how she is received by patients and other care providers. For example, an intervener who is curt and impersonal is unlikely to engage patients on psycho-social or personal issues.

The care provided is obviously intended to impact the outcomes, as this is the primary reason for providing the intervention. The theory-driven approach acknowledges that the work of nursing interventions is often on different levels, as is consistent with the findings of a comprehensive and extensive research project to describe public health nursing (Keller et al., 2004). Sidani and Braden (1998) describe micro and meso levels of care. The micro represents the patient level, when the intervener is focussing on patients and/or their families. The meso level is directed at care providers involved in the patient's care or at the healthcare system (e.g. managing communication, coordination or continuity) (Sidani & Braden, 1998). In developing an operationalised framework, the researcher aims to identify key variables which represent selected care processes which impact outcomes.

The setting is understood to potentially influence the care provided, and outcomes received. Of interest are the physical and psychosocial features of the environment. Acknowledging the setting's potential impact on outcomes is vital for the external validity of effectiveness findings of interventions (Sidani & Braden, 1998). The setting may enhance or inhibit the outcomes, as well as impacting the way in which interventions are provided. In developing a framework, the researcher aims to identify setting characteristics and the nature of their influence on outcomes. Ideally, a base of what is required to implement the intervention effectively should be named up (Sidani & Braden, 1998). For example, specify certain physical and psychosocial setting features, client characteristics, and intervener skills and attributes.

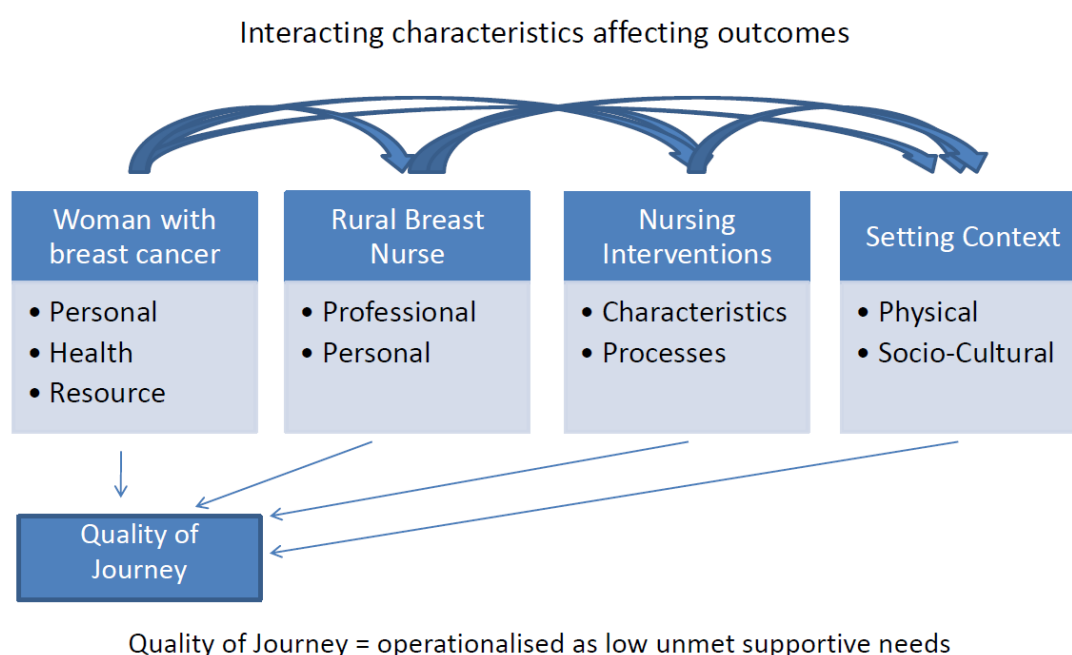
Outcome variables influence the conclusions regarding intervention effectiveness. The selection of outcome variable(s), measurement tool(s), and timing of measurement(s) influence the findings, and the validity of those findings (Sidani & Braden, 1998). The purpose and the desired effects of the intervention are important to consider when selecting outcome variables. Criteria used to assess the effectiveness can range from clinical endpoints, functional status, and/or perceptual outcomes of patients (Sidani & Braden, 1998). Outcome variables can be objective



or subjective, and intended or unintended. The specificity of the outcome variable and its measurement tool potentially influence findings and therefore should be considered carefully by researchers with the aim of selecting a responsive variable and measurement tool.

A schematic diagram representing the generic conceptual framework as it relates to this thesis is at Figure 1. This figure is an interpretation of Sidani and Braden's (1998) text based ideas. They did not represent their generic nursing intervention framework graphically.

**Figure 1: A diagrammatic representation of Sidani and Braden's approach (1998) applied to rural breast nursing interventions**



The aim of this study is *to advance knowledge of rural breast nurses' practice in real world contexts*. Towards this aim, this study will produce generalisations which can be applied to the developing intervention theory. Data within this study were analysed in an attempt to produce an analytic generalisation, although the data is recognised to be context- and time-dependant.

## Chapter Four: Methods

The previous chapter described the philosophical perspective within which this research was undertaken. The research methods logically fall from the methodology. This Chapter describes the methods used to provide data to investigate the research questions. It provides assurance that the appropriate procedures were followed. This chapter presents the methods utilised to undertake the research. Sections describe the research design, sample and setting, tools, procedures, analysis and ethical considerations are presented, along with the limitations and weaknesses of the approach taken.

The research questions framed within the pragmatic philosophical perspective determined the methods undertaken. This thesis addresses the following overarching question, and sub-questions:

**What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?**

- a) To what extent do women consulting RBNs have their supportive care needs met?**
- b) What are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?**
- c) How do RBNs describe their nursing practices, and what factors influence their practices?**

Table 2 presents a comprehensive methodology table demonstrating the links between research questions, framework components, data collection tools, data, sampling and analysis strategies.

**Table 2: Comprehensive methodology table**

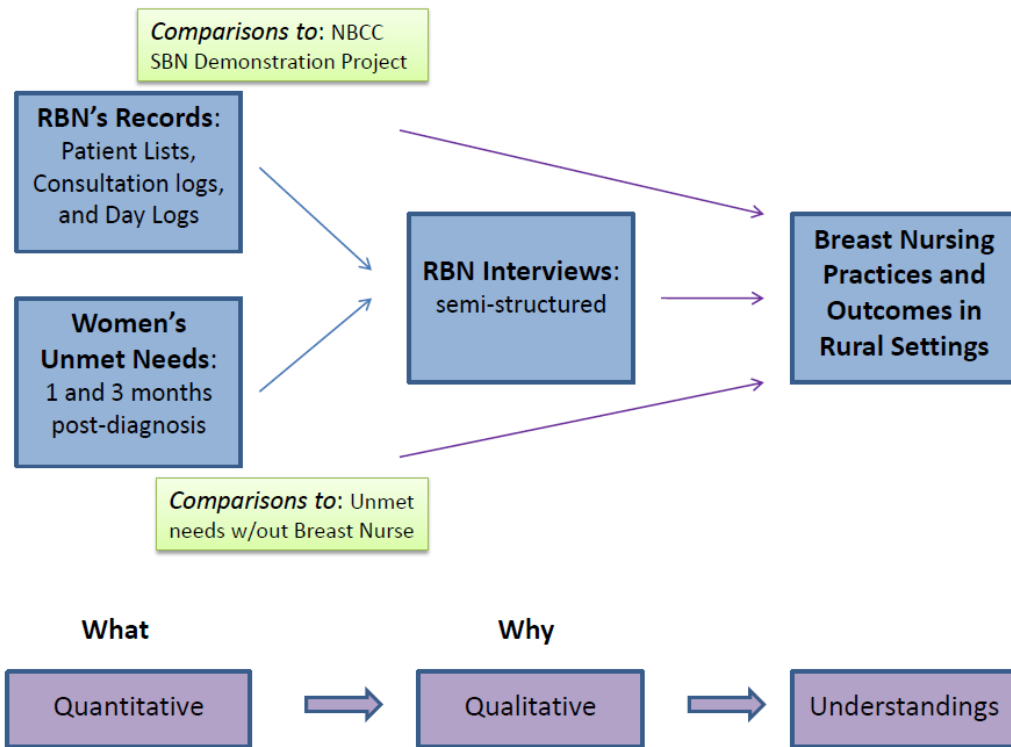
Component	Element of	Data Collection Tools	Data	Sampling	Analysis
OUTCOMES – quality of journey	Operationalised as relatively low unmet supportive care needs	Supportive Care Needs Survey (SCNS)	Moderate or high unmet supportive care needs (inc mean #, changes to mean, domains means)	Whole of population (i.e. all women fulfilling the eligibility criteria with early breast cancer consulting a RBN in Tasmania); One month and three months post diagnosis	Descriptive statistics – percentages, means; Comparative Statistics – tests of statistical difference.
CLIENT – Women with breast cancer	A) Personal B) Health / Disease Profile C) Resource	Demographic and medical characteristics section within SCNS	A) Age, gender B) Cancer treatments received, remission status C) Marital status	Whole of population (i.e. all women fulfilling the eligibility criteria with early breast cancer consulting a RBN in Tasmania); One month and three months post diagnosis	Descriptive statistics – percentages who fell within each category
		Semi-structured interviews with RBNs	Themes relating to the client characteristics as described by RBNs	Whole of population (all RBNs who had and/ were working as a RBN in Tasmania); 2 years following quantitative data collection	Thematic analysis
INTERVENER – Rural breast nurses	A) Personal B) Professional	Semi-structured interviews with RBNs	Themes relating to the intervener characteristics as described by RBNs	Whole of population (i.e. all RBNs who had and/ were working as a RBN in Tasmania); 2 years following quantitative data collection	Thematic analysis
		Researcher's Observation / Knowledge	Description of professional roles held by RBNs		Personal observation
INTERVENTION – Nursing Practices	A) Micro i.e. with clients B) Macro i.e. overall duties	Consultation Logs (micro)	Consultation emphasis, initiation source, timing, contact mode, interventions (written & referrals), duration,	Whole of population (i.e. all RBNs working in the role in Tasmania); one year data collection	Descriptive Statistics – %, total, mean, averages.
		Study Patient Lists (micro)	# and timing of consultations per client		Descriptive Statistics – means, totals.
		Day Logs (macro)	Practice hours, time spent on various duties (with and without clients)		Descriptive statistics – average, %, mean, total..
		Semi-structured interviews with RBNs (micro & macro)	Themes relating to micro and macro intervention characteristics	Whole of population (i.e. all RBNs who had and/ were working in Tasmania); 2 years following quantitative data collection	Thematic analysis
CONTEXT – Regional healthcare context	A) Physical B) Socio-cultural	Semi-structured interviews with RBNs	Themes relating to the regional healthcare context characteristics as described by RBNs	Whole of population (all RBNs who had and/ were working in Tasmania); 2 years following quantitative data collection	Thematic analysis
		Researcher's Observation / Knowledge	Description of physical healthcare contexts		Personal observation

## **4.1. Research Design**

The fundamental decisions made for using mixed methods in this study are detailed in this chapter, and briefly summarised here. The decisions about weighting, positioning, and mixing of quantitative and qualitative data were made prior to data collection. The quantitative and qualitative data received equal weighting. The data collection was sequential, with quantitative leading to qualitative data collection. The strands of data were first analysed separately, then analysed together at the final integration. Data strands were also integrated or 'mixed' in that quantitative results informed qualitative data collection. The two types of data were connected as the majority of RBN participants were involved in both quantitative and qualitative data collection.

The investigation explored rural breast nursing practices, unmet supportive care needs, and specifically client, RBN, and setting factors that influenced nursing practices and client outcomes. The study used a sequential, explanatory, and mixed method design, the most straightforward of the mixed method designs (Creswell, 2003). The research was undertaken in two phases, with the quantitative component first, followed by a qualitative component which was informed and driven by the quantitative results. The quantitative phase provided descriptions of breast nursing practices and outcomes for women, while the qualitative phase explored why nursing unfolded the way it did. Figure 2 provides a visual depiction of the research design by presenting the schematic diagram. As this study was in the natural setting, the lack of equivalence between client sub-group populations could not be controlled and no manipulation of variables was involved. The researcher did not have control over breast nursing practices.

**Figure 2: Methodology schematic diagram demonstrating sequential, explanatory mixed method design**



Multi-analysis was used (i.e. both quantitative and qualitative data analysis). The area of primary interest for the analysis was the process, thus a process / experience oriented analysis framework was utilised, namely “evaluating processes or experiences pertaining to one or more cases within a specific context over time” (Onwuegbuzie, et al., 2009, p.117-118). A non-cross-over mixed analysis, where both types of data were collected and each was analysed using its own traditional paradigmatic analysis, was used rather than cross-over mixed analysis (e.g. when qualitative and quantitative analysis are mixed using different paradigmatic traditions). This suited the sequential nature of the data collection. Priority /

weighting status of the data type was essentially equal in respect to contributions, although there was more quantitative data collected to analyse.

Several strategies were used to provide comprehensive data about breast nursing practices, including overall nursing practices and those in consultation with women. RBNs recorded quantitative data about their overall practices and consultations over a one year period in Tasmania, Australia. RBNs completed Day Logs one week per month, and Consultation Logs for every potential study patient over the one-year period. Additionally, RBNs completed Study Patient Lists indicating when consultations were undertaken in relation to a women's breast cancer journey. Comparisons were made with the NBCC SBN Demonstration Project whenever possible (SBN Project Team 2000). Together the Logs and Lists addressed the sub-question: *What are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?*

Supportive Care Needs Surveys from two time-points provided a story of changing unmet needs. These surveys addressed the sub-question: *To what extent do women consulting RBNs have their supportive care needs met?* The longitudinal nature of unmet needs within a cohort had not yet been explored in the literature until this study (Minstrell et al., 2008). The scientific journal article arising from this thesis is available at Appendix 1.

Semi-structured interviews focused on understanding breast nursing from the RBNs' perspectives. This qualitative element addressed the sub-question: *How do RBNs describe their nursing practices, and what factors influence their practices?*

"Qualitative interviewing is appropriate when the purpose of the research is to unravel complicated relationships..." (Rubin & Rubin, 1995, p.51). Understanding the influences on breast nursing practices helps service planners and managers to appropriately shape and support nursing services with an awareness of the many influences on nursing practices.

The components of this study were integrated using several methods. The quantitative and qualitative methods were mixed by both connecting the data (i.e. quantitative -> qualitative) and merging the results during interpretation. The quantitative results shaped the development of the topics and approach of the qualitative data collection phase. Therefore the two sets of data were connected prior to the interpretation stage (Creswell & Plano Clark, 2007). Additionally, the components of the study were integrated through individuals participating in both phases, namely qualitative phase RBN participants were those that participated in the quantitative phase (plus one purposive addition).

The integration of the mixed methods was also at the data interpretation stage with the merging of the results during interpretation (Creswell & Plano Clark, 2007). The meta-inferences made during the data interpretation stage addressed the research question: *What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?* Integration during the interpretation stage is consistent with sequential explanatory designs (Creswell, et al., 2003, p.224). Importantly, the pragmatic philosophical base allowed for the integration of mixed methods at any stage in the research process (Bazeley, 2009). Consistent with the typical sequential explanatory design, the major integration in this study is undertaken during the interpretation stage (Creswell, et al., 2003).

#### **4.1.1. Sampling Strategy**

A multi-level mixed methods sampling strategy was undertaken, with the primary approach being purposive sampling utilising a complete collection (criterion) sampling technique (Patton, 2002). Purposive sampling is consistent with the qualitative tradition. Cases were based on the rural context rather than randomly selected. Data was collected on three levels: women, RBNs, and settings across three sites.

Stratified purposive sampling guided the first quantitative RBN phase of data collection. The sub-group of RBNs was selected for the study's focus. Three RBN service sites were identified, namely *Community*, *Private Hospital*, and *Public/Private Hospital*. A complete collection (criterion) sampling technique was used, in that all RBNs fulfilling the criterion (employed as an RBN in Tasmania) were invited to participate.

Purposive cluster sampling guided the sampling of women for quantitative data collection. Again, complete collection sampling was used to include all women with early breast cancer consulting an RBN to participate. Clusters of women were linked to the aforementioned RBN sites.

Purposive sampling was used again in the final qualitative phase. This time, all RBNs who had participated in the initial phase employed as an RBN, and/or subsequently were employed as a BN in Tasmania were invited to participate<sup>12</sup>. Furthermore, the researcher collected contextual information based on the stratified sampling strategy, reflecting three different healthcare regions / zones.

The sampling strategy led to large variance in sample sizes across research strands, which is reportedly common in mixed methods studies (Teddlie & Tashakkori, 2009). The quantitative phase included six nurses at the RBN level, and 74 (time one) and 83 (time two) women at the client level, and the qualitative phase had a sample size of six at the RBN level. A sampling strategy flow chart is provided in the next section.

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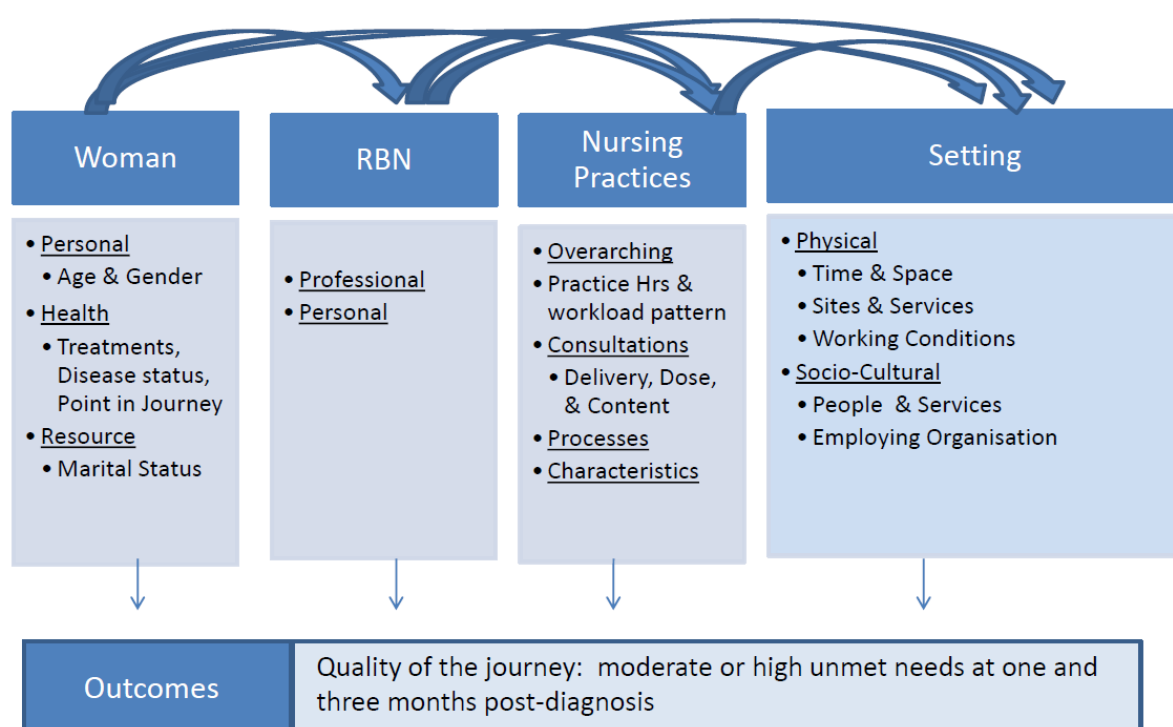
<sup>12</sup> This phase led to a cross-over of one RBN service type (i.e. community nursing) to another context previously isolated to private hospital rural breast nursing.



## 4.2. Relationship between Methods and Conceptual Framework

Data was collected which fit within the generic nursing intervention framework provided by Sidani and Braden (Sidani & Braden, 1998). The section describes how the framework elements were conceptualised within this thesis. Specifically this section describes the conceptual framework as it relates to the data collected to develop the framework for rural breast nursing practice. Figure 3 presents the data variables were collected for each conceptual component.

**Figure 3: Data collected to populate theory-driven approach**



This thesis aims *to advance knowledge of rural breast nurses' practices within real world contexts*. A theory-driven intervention framework was developed for research in the naturalistic setting in an effort to build on what was known about nurses' work to support women with breast cancer, and expand learnings to rural contexts. Thus this research project results in a conceptual framework backed by research with special insights for the rural context.

#### **4.2.1. Outcomes**

Women present to the RBN with a variety of issues which can range from an actual problem (e.g. treatment distress), potential problem (e.g. lymphoedema), to a problem which might only be able to be managed (e.g. cancer treatment related fatigue). The aim of the RBN is to prevent, resolve and manage the health status of their clients with early breast cancer. Thus, the intended outcomes are many, ranging from resolution of an actual problem, the minimisation and management of an actual problem, and/or absence of a potential problem that was prevented.

By meeting supportive care needs as the intermediate measure, women with breast cancer presumably have an improved cancer journey with less morbidity as the ultimate aim. “Intermediate outcomes are those changes that result from the intervention that are presumed to contribute to or create a facilitative climate for the attainment of the ultimate outcomes” (Sidani & Braden, 1998, p.146).

Additionally, fulfilled or little need for access to services can be seen as an intermediate step which one would anticipate would lead to improved experiences for women. It has been postulated that access to services decreases high unmet needs, as the services assist in the resolution of unmet needs (Foot & Sanson-Fisher, 1995). Thus the exploration of unmet needs for access to services is warranted as an outcome measure.

The key operating outcome variable utilised in the conceptual intervention framework are supportive care needs, more specifically moderate or high unmet supportive care needs and needs for access to services. Outcomes variables “reflect the goals of interventions and care to promote, maintain, and enhance the health of patients. Therefore, outcomes that are health oriented and patient-centred, and that are consistent with the holistic nursing perspective, are of interest” (Sidani & Braden, 1998, p.63). The intended outcomes of the breast nursing practices are to lower the unmet supportive care needs of their clients through direct and indirect interventions. This is based on the theory that by meeting clients supportive care needs, RBNs and other healthcare providers can improve women’s journey with

breast cancer (i.e. minimising their morbidity is the focus). Moderate or high unmet supportive care needs were collected at two points in the cancer journey, allowing for patterns of changes to unmet needs to also be identified. The first survey point is after participants have consulted with an RBN at least once, where the second is likely to have included multiple contacts, as well as changing treatment circumstances for the woman.

This study relies on clients' perceptual outcomes related to their general well-being and satisfaction with the broad supportive care received across services, sites, and experiences related to their diagnosis of early breast cancer. The outcome data are subjective variables obtained from the client and "requiring the client's personal judgement..." (Sidani & Braden, 1998, p.140).

It is important to note that the outcome variable is not specific to breast nursing practices, instead a generic assessment of participants unmet supportive care needs, which potentially are influenced by all healthcare providers, sites, and services. The SCNS is a multiple item response measure which reflects various domains of supportive care needs, and can be viewed as reflecting the quality of care and women's specific responses to disease, cancer treatment, and supportive care. "Generic outcomes are useful when assessing the quality of healthcare at a macro level of analysis, such as when examining the impact of a new nursing care delivery system..." (Sidani & Braden, 1998, p.145). Although the outcomes data measure used in this study could have been more specific and therefore more sensitive to assess the specific BN intervention, the measure was intended to take a more holistic and comprehensive assessment of the quality of care received. One of the advantages of the generic assessment provided by the SCNS is that it is useful for comparisons. The SCNS results can be compared with the results of different client populations with similar and different cancer diagnosis and time since diagnosis.

#### **4.2.2. Nursing Practices**

Key operating intervention variables relate to the components and the strength of the intervention. The variables relate to RBN intervention on two levels: directly with clients (micro level) and with the broader healthcare system and general use of time (meso level) (Sidani, et al., 2004). The micro level variables relate to the delivery, dose, and content of consultations with clients. Specifically, the micro level variables of interest are the total number of consultations received, when in the cancer journey they occur, resources provided, and the average duration, who initiates, the mode (i.e. phone or face-to-face), and the content of consultations. The meso level operating variables relate to practice hours per client and workload distribution (i.e. overall use of RBN time for various patient and non-patient related duties). Additionally, the above quantitative micro and meso operating variables are explored further in semi-structured interviews with RBNs. Thereby identifying what RBNs perceive they do to support their clients' needs being met on micro and m levels, and a general descriptor of their intervention.

Processes underlying the RBN intervention's effectiveness, or how the intervention works, give rise to the key operating process variables. "Conceptually, they indicate the mechanisms responsible for producing the favorable, intended outcomes. They indicate what nurses do for, with, or on behalf of patients that make a difference in or lead to improvement in health status" (Sidani & Braden, 1998, p.62). To access key process variables, the researcher interviewed RBNs for their perceptions of the characteristics of care and intervention processes to identify qualitative variables. These process variables represent difficult to measure, often subjective, features of the RBN care, yet are deemed important for receiving intended outcomes.

#### **4.2.3. Influential Characteristics of Women, RBN, and Setting**

Key operating variables for extraneous features include those related to the client, intervener, and the setting. All contain characteristics which have the potential to impact the intervention, processes of care, and ultimately outcomes. The

extraneous variable potential impacts are discussed below, as well as which key operating variables were explored in this research framework.

Clients, their personal and health characteristics, influence the treatments undertaken and outcomes received. Differences in client characteristics affect susceptibility to adverse outcomes, and the nature and extent of a client's presenting issues. These in turn affect RBN interventions delivered through the client's preferences, acceptance, and response(s) to the interventions delivered. The nature of the proposed treatment is likely to vary as individuals present with a different range and extent of issues. Clients' preferences and responses shape the treatment plan undertaken and the responses to treatment, and thus the outcomes received.

The key operating variables related to the client's features were personal, health and resource related. Women's age and gender (personal), treatments received, disease status, and point in cancer journey (health), and marital status (resource proxy) were collected at each survey time point. Women's unmet supportive care needs, also a key outcome variable, was also key information for understanding what issues clients' might be bringing to their consultations. Furthermore, key client operating variables were described from semi-structured interviews with RBNs.

The personal and professional characteristics of the RBN, as the intervener, influence the outcomes attained for women with breast cancer. A nurse's style and approach may impact a client's response to her, for example what a client feels comfortable bringing up as an issue. The RBN's education and experience can influence her identification of issues, and the type and manner the nurse ultimately provides the processes of care. Additionally, the RBN may impact the psychosocial context within which she works, or the ways in which other services or providers respond to her. It is also possible that the nurse's personality and actions actually shape the physical context in which she works.

The key nurse variables related to professional and personal characteristics. Professional features were previous and present professional roles obtained from researcher's observations and/or semi-structured interviews. The professional features were objective, whereas the personal features were more subjective. Key personal variables extracted from interviews included such characteristics as comfort with their own and/or others' emotions.

The setting also has the potential to influence intervention, processes of care, and ultimately the outcomes for women with breast cancer. Key setting variables were characterised as physical or socio-cultural factors. Descriptions of the physical healthcare contexts were obtained by the researcher's observation and related to the proximity and access to various specialists, services and healthcare sites. These physical features were reinforced through RBN interviews, which also provided the basis for key socio-cultural setting features.

Within this thesis, the researcher describes factors that influence nursing practices and outcomes. This study extends the generic nursing conceptual intervention framework arising from the theory-driven approach by providing further description of and explanation for breast nurses' practice in rural settings.

### **4.3. Sample and Setting**

This section describes the samples from whom data was collected and the settings where the participants worked and lived. The study was conducted within the primarily rural island state of Tasmania, Australia. Participant selection was population-based, thus selection bias was minimised. The study included two sample populations, women with breast cancer and RBNs. The results can therefore be understood as generally representing the breast nursing practices of Tasmanian RBNs and the experiences of the women consulting them. Figure 4 visually presents the sampling flow chart.

Participant Schematic: Sites, Rural Breast Nurses and clients across Tasmania

Far left column denotes data collection tools, vertical patterns follow RBN Sites, RBNs and clients within each region

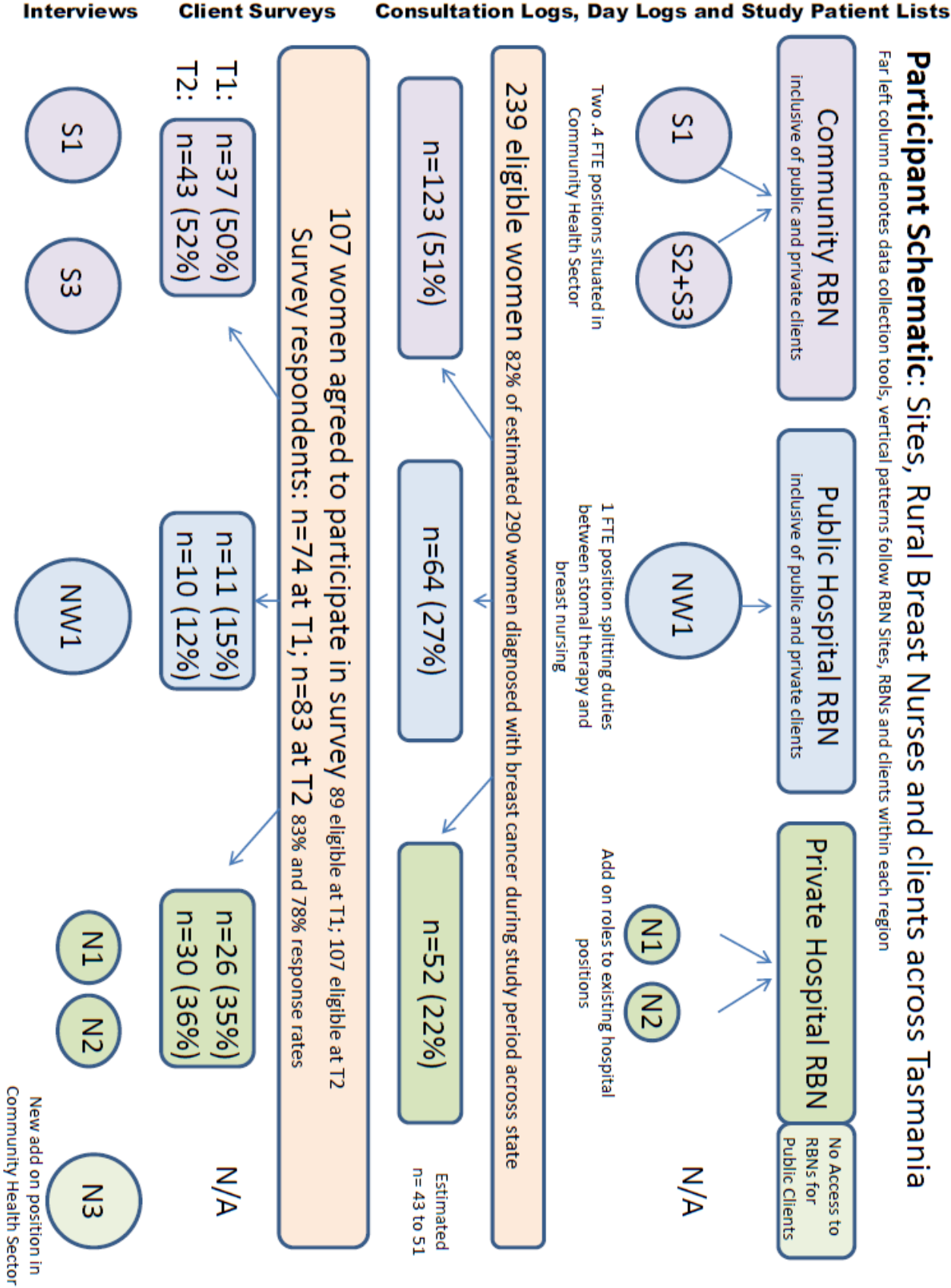


Figure 4: Sampling and participant schematic diagram

\* It is not known how many of the 239 clients were actually eligible (e.g. fit within the one month and three months post-diagnosis timeframes of consulting an RBN).

Women with breast cancer consulting with a BN in Tasmania for early breast cancer during the study period were eligible to participate. Patients were excluded if they were 18 years of age or under and/or if their English language abilities would inhibit their completion of the Supportive Care Needs Survey. During time one (T1) 74 of 89 eligible participants returned surveys, while during time two (T2) 83 of 107 eligible women participated (78% and 83% response rates respectively). Sixty-three women returned both time one and time two surveys. As RBNs recruited women with breast cancer, it is unknown how many eligible women were invited to participate, declined participation, and/or RBNs chose not to invite.

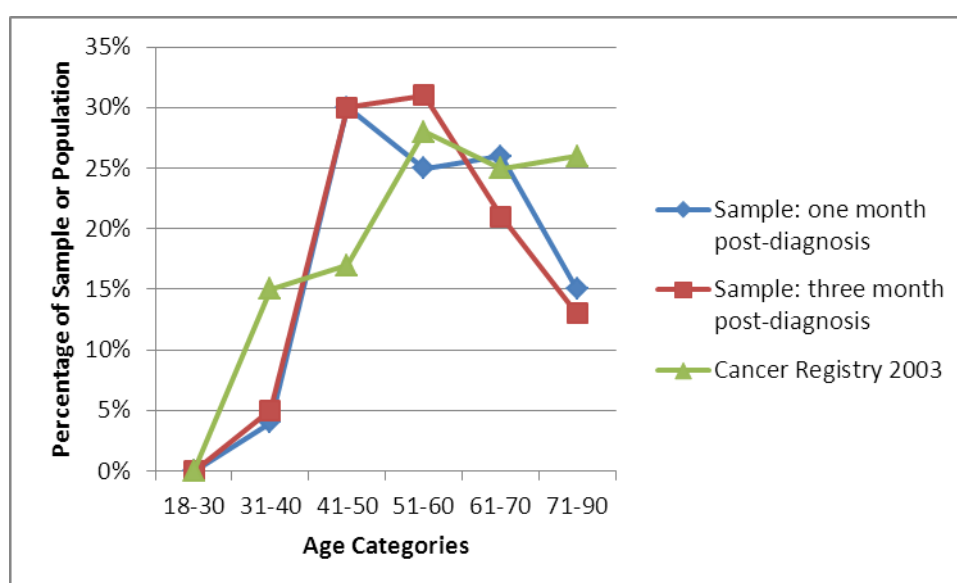
Based on the prevalence figures from the Tasmanian Cancer Registry Data, it is estimated that 290 women were diagnosed with breast cancer in the study area during the study period (i.e. one year spanning 2003-2004). As the study period cut across two registry years, the exact number of women diagnosed during the study period is unknown. It is estimated that 85% would have had access to one or more RBN (all women within the *Public/Private Hospital* and *Community RBN Site* regions, and half of those from within the *Private Hospital RBN Site* region) – but not necessarily all women knew about and/or chose to utilise the service. This would have resulted in approximately 247 eligible participants (i.e. 85% of 290 women). The RBNs reportedly consulted with 239 clients with early breast cancer (data obtained from RBN held study patient lists). Thus, it is estimated that approximately 50 women diagnosed with early breast cancer during the study period did not access an RBN.

The representativeness of respondents who completed SCNS was analysed. By qualitatively comparing the age and regional distribution of these study samples with the cancer registry (Newman et al., 2006), the respondents' representativeness

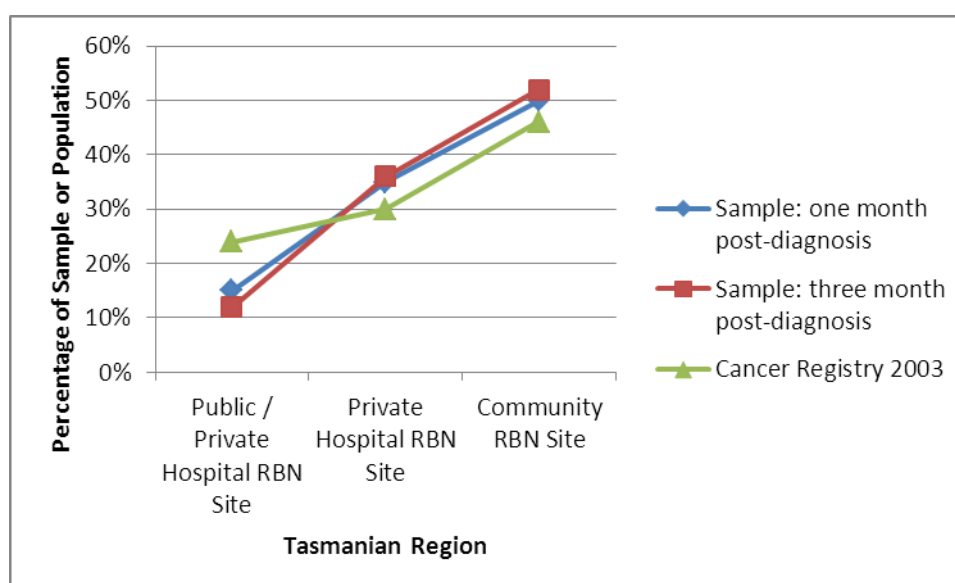


of the Tasmanian early breast cancer population is better understood. Figure 5 and Figure 6 display the age and regional representativeness of the samples as compared to the Tasmanian cancer registry data. The proportion of respondents from within each region appears representative, especially considering only half of northern women with breast cancer had access to a BN and thus were able to participate. The study samples differed in age from the registry data in fewer respondents proportionally in the 31-40 and 71-90 age ranges and more in the 41-50 age range. The 51-70 age range was proportionally very similar between study samples and the Tasmanian registry population.

**Figure 5: Age representativeness of SCNS samples**



**Figure 6: Regional representativeness of SCNS samples**



Importantly, all nurses employed as an RBN in Tasmania during the study participated in the research project. Eligible nurse participants included RBNs employed in this role within Tasmania, Australia<sup>13</sup>. All participating RBNs had completed an accredited breast care nurse education course. Six RBNs participated in the phase one portion of the study. These nurses fulfilled five breast nursing roles over the one year quantitative data collection. One RBN resigned from her position (S2) and was replaced by another (S3).

Of the six RBNs who participated in quantitative data collection, all but one also participated in the qualitative data collection (phase two). Thus, five RBNs participated in both phases of the study, enabling a connection of quantitative and qualitative data. In total, six RBNs participated in qualitative data collection. They represented all four RBNs employed in the role at the time, the three RBN sites studied during phase one, and an additional RBN in the midst of establishing a new practice (N3). The additional informant was included as this was a new position

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<sup>13</sup> Consistent to what was reported in Chapter One, Tasmanian BNs held a multitude of titles as well. For simplicity, these have all been entitled RBNs for this study.

established since the quantitative data collection<sup>14</sup>. A visual representation of individual RBN participation in quantitative and qualitative strands is at Figure 4.

#### **4.3.1. Comparisons with Other Studies**

Results from previous studies were used for comparison to better understand the results of this research project. The NBCC SBN Demonstration Project's results were used to compare BNs use of time and consultation activities. Two important differences between these samples were that those in the NBCC Project demonstrated the implementation of SBN clinical pathway protocol, and six of the seven SBNs were based in city centres rather than rural hospitals or settings. By contrast, the RBNs in this study were all rurally based.

Results comparisons were also made with the unmet supportive care needs of people with cancer. The study samples used for comparison are described in Chapter Five. Specifically, a previous SCNS study involving women with breast cancer in urban and rural Australia was the most comparable reference sample (Girgis, et al., 2000). Reference values can serve as a benchmark against which data can be compared. These results provide a "guide as to the scores you might expect to see for a given cancer population with specific characteristics" (Boyes et al., 2006). An important difference between respondents in this study and other reporting SCNS results is that these women were receiving supportive care from a BN.

#### **4.4. Tools**

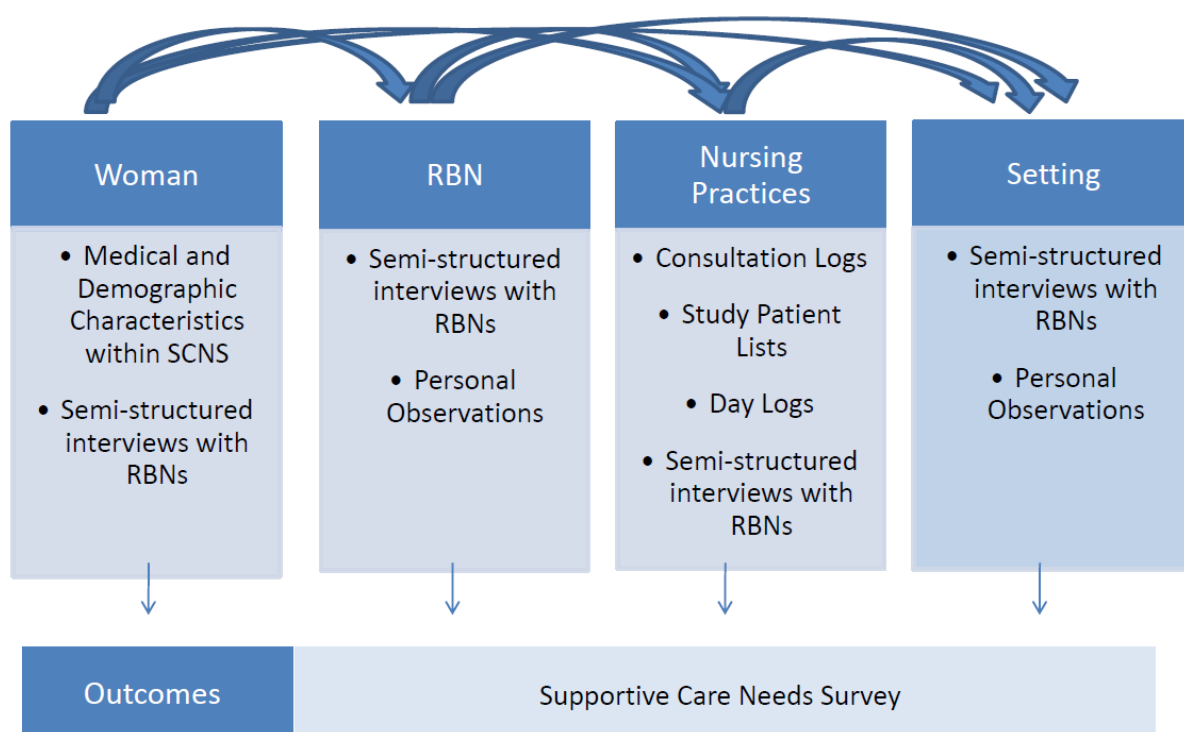
This section describes the data collection tools utilised in this study. Some tools had been designed and utilised previously in published research, whereas others were developed by the researcher and used for the first time in this research project. The tools were completed by participating women with breast cancer and RBNs. The

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<sup>14</sup> There was a 2 year time lapse between quantitative and qualitative data collection.

data collection tools include the Supportive Care Needs Survey, Consultation Logs, Day Logs, Study Patient Lists, and Semi-structured Interviews. Figure 7 presents the data collection tools utilised to populate the conceptual intervention framework.

**Figure 7: Data collection tools utilised within this study to populate the conceptual intervention framework**



#### 4.4.1. Supportive Care Needs Survey

The Supportive Care Needs Survey (SCNS) was administered to women to assess the effectiveness of rural breast nursing practices (and the healthcare team) at meeting the supportive care needs of breast cancer clients. In the SCNS, respondents retrospectively rate their needs over the past month. The survey collects clients' perceived levels of unmet needs. The survey also collects demographic and medical information such as age, time since diagnosis, and treatments received. The SCNS takes approximately 15 to 20 minutes to complete (Bonevski et al., 2000).

The SCNS was designed to provide a “comprehensive assessment of the multidimensional impact of cancer including assessment of health services and treatment delivery” (Bonevski, et al., 2000). It directly assesses patients’ needs and measures the magnitude of need. The survey collects people’s self-reported levels of need as respondents retrospectively rate their needs over the past month for each of 59 items within a five-point Likert scale: no need, need met, low need, moderate need, or high need. The SCNS has 5 domains, namely Psychological (22 items), Health System and Information (15 items), Physical and Daily Living (7 items), Patient Care and Support (8 items), and Sexuality (3 items). The SCNS has proven to be psychometrically sound with face and content validity, and internal reliability with Cronbach alphas for the factor-based scales ranging from 0.87 to 0.97 (Bonevski, et al., 2000). A 16-item supplementary module (McElduff et al., 2004) was included in this study to assess needs for better access to healthcare and ancillary support services. Basic demographic and medical characteristics were also collected by questionnaire (including age, treatments received, marital and remission status).

Important factors to assessing any data collection tool include reliability and validity. Reliability is the ability to "provide consistent scores on repeated administration" and validity is the "ability of the instrument to measure that which it is intended to measure" (Bonevski, et al., 2000, p.218). The validity and internal reliability of the SCNS have been demonstrated. This needs assessment tool has the ability to directly assess of clients’ needs and measure the magnitude of need which allows for prioritization (Bonevski et al 2000).

The SCNS was developed with the aim of determining the prevalence of perceived unmet needs of cancer patients. The tool utilises similar domains as those identified based on previous studies (Ferrell et al., 1997), and has been used in many studies across Australia with a range of sample populations (Beesley et al., 2008; Girgis, et al., 2000; Sanson-Fisher et al., 2000; Steginga et al., 2001). The full SCNS, including the access to services, and medical and demographic modules, is

attached at Appendix 2. The specific items relating to each domain are listed in Appendix 3.

#### **4.4.2. Consultation Logs**

This research instrument captured breast nursing practices in client consultations. This included the treatment phase during which consultations occurred (i.e. consultation timing), consultation length (duration), written resources provided to patients, referrals made by RBNs, whom initiated the consultation (i.e. initiation source), and whether the consultation was face-face or over-the-telephone (i.e. delivery mode). Consultation Logs contained a list of breast nursing duties, and provided space for nurses' comments. Additionally, nurses were asked to record up to three areas of consultation emphasis so that an understanding of the primary focus of the consultation could be gained (i.e. domain emphasis). The Consultation Log is attached at Appendix 4.

This data collection tool was designed by the researcher to identify the breast nursing practices of RBNs in consultations with women with breast cancer. The Consultation Log was developed by using the breast nursing activities listed in the SBN clinical pathway protocol by the NBCC SBN Demonstration Project (SBN Project Team 2000), and organising them within the domains of clients' supportive care needs identified by SCNS developers (Bonevski, et al., 2000). Common breast nursing activities were clustered by the researcher into the needs domains they were expected to most commonly address. Different numbers of activities related to each domain. For example, twelve actions addressed Psychological domain issues whereas only four actions addressed Sexuality issues. Breast nursing practices were thus organised within supportive care needs domains (see Appendix 4 for which activities were clustered within which supportive care domains).

Written resources were categorised for ticking, as were referrals provided. Both written resources and referrals were also provided an 'other' category with space to name the service(s) referred to and/or written resources provided.

RBN participants reviewed the Consultation Logs prior to their use within the study, and assessed it to be understandable and easy to use. Nurses provided feedback that they anticipated the Logs would be a useful document to collect client information since no form had been used to date for collecting and storing client consultation information. No other reliability testing was performed.

#### **4.4.3. Day Logs**

The purpose of Day Logs was to describe RBNs overall amount and distribution of time across duties. Work sampling is a valuable methodology to define nursing practices (Pelletier & Duffield, 2003). While clinician record keeping of time spent on various duties has its problems, it was the best means identified within this study due to resource constraints. Day logs are known to lack precision in data collection, however they provide reliable general indication of time use (Pelletier & Duffield, 2003). The choice to use week-long continuous sampling once a month by RBN participants was made for multiple reasons. Specifically, continuous time sampling is considered more accurate than time interval sampling e.g. every half hour, as frequent but short activities are more often missed (Mann et al., 1991). Additionally, time recording obtained by researcher observation had the potential to skew the results based on the effect of the observer on the observed, i.e. the researcher on the RBN (Barker, 1980).

Participating RBNs completed Day Logs to capture the amount of time spent on the various breast nursing duties. The number of RBN hours worked were recorded, whether the day was representative of a typical day, and the amount of time spent on various breast nursing activities. Information collected included the time spent on various activities falling into two broad categories, patient related and non-patient related duties.

Patient-related duties included clinical duties (e.g. wound assessment), supportive (i.e. sitting in with doctor), supportive care (i.e. providing information and support) face-to-face and over the telephone, documentation, verbal staff hand-over, and

referrals or appointments (i.e. patient-related phone calls). Additionally, other patient related duties included patient contact not included elsewhere, leading support groups, and multidisciplinary meetings. Time spent on non-patient related duties were categorised as administration, education (i.e. teaching others or acting as a resource), education (i.e. personal development), debriefing, staff meeting, other staff contact, meetings, work related travel, research related activities, and other.

The Day Log data collection tool was modified slightly<sup>15</sup> from the one used by the NBCC SBN Demonstration Project (SBN Project Team 2000), yet effectively remained the same. This allowed for direct comparisons of results. No validity or reliability testing was done on the original tool produced, nor were they done in this study. The Day Log utilised in this study is attached at Appendix 5.

#### **4.4.4. Study Patient Lists**

The purpose of this simple data collection tool was to record every contact each woman received from the RBN, and when in the cancer journey they occurred. With Study Patient List data, the researcher was able to determine the number of consultations undertaken with each woman, and when in the cancer journey they were undertaken. The data collected included the name of the women with early breast cancer, the client's date of breast cancer diagnosis, their individual code provided by the RBN, and ticks for consultations undertaken during specified treatment phases (those from the NBCC SBN '5 in 12' clinical pathway protocol), and for those additional to the standard consultation phases (categorised as 'other'). 'Other' consultations were categorised as either patient or nurse-initiated. The list also assisted RBNs to identify if they had invited women with breast cancer to participate in the study. The client's names and date of diagnosis were used for

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<sup>15</sup> Specifically, the researcher added a spot for RBNs to record their research identification number.



RBN reference, and then excluded when forwarded to researchers to maintain confidentiality. The RBN-held Study Patient List is at Appendix 6.

#### **4.4.5. Semi-Structured Interviews**

The purpose of the semi-structured interviews was to extend the knowledge gained in quantitative data collection, and understand what influences breast nursing practices. Although other qualitative data collection methods were considered, semi-structured interviews were determined to be the most effective means of attaining the desired experiences and opinions. For example, focus groups data collection could have provided potential beneficial interactions between RBNs and saved researcher time (e.g. data collection and transcription time). However, focus groups can be dominated by overbearing individuals and have tendencies to lead towards normative discourses (Smithson, 2000). Of specific concern to the researcher, focus groups would have lacked confidentiality, limited the detail provided by each RBN, and lacked practicality for RBNs given they were spread out across the state.

Additionally, the semi-structured element of the one-on-one interviews allowed the researcher to guide discussion while allowing for and capturing variability in RBN responses and experiences. Therefore a more structured process would have limited the researcher's responsiveness to RBN's experiences and insights, and a less structured approach could have missed key themes of interest.

The topics of discussion and inquiry of semi-structured interviews were derived from the quantitative results of the aforementioned quantitative tools. The interview template guide was formulated by the researcher after quantitative data collection and preliminary analysis was complete. The preliminary results from SCNS, Day Logs, Consultation Logs, and Study Patient Lists assisted in shaping the interview questions and themes.

Semi-structured interviews with RBNs were held to understand how RBNs describe their breast nursing practices, and what factors influence these nursing practices.

Interview topics emphasised RBNs' understandings of their contribution to meeting supportive care needs. Specific areas of focus included the extent of their ability to influence supportive care needs, and mediators – enablers and inhibitors – of their abilities, as well recruitment issues, history and future of breast nursing in their region. The interviews were also used to identify structural barriers and other impediments to the provision of supportive care.

The researcher used an interview template to guide her questioning, listening and silence. The semi-structured interviews were around four broad areas of inquiry: the extent of their ability to meet needs; decision-making; mediators on their effect; and the context. Informants were asked to describe how they went about supporting their clients' supportive care needs, and which areas they found most challenging. The nurses were asked about how they made decisions about what to do, and how tasks / pressures were prioritised. Informants were probed about what factors enhanced or impeded their ability to provide the best breast nursing care possible. Finally, RBNs were asked to describe elements within their regional setting that impacted how they went about their duties. See Appendix 7 for the Interview Template.

The researcher was interested in RBN understandings - and her own interpretations, and their accounts of behaviours, nursing practices and attitudes of RBNs. The researcher recognises the study has a sharp resolution with a narrower scope. It is believed that depth is available from these interviews with researcher and nurse having worked together for many years in relationships of reciprocal respect and trust. Breadth was attained as the interviews covered the full extent of RBN roles across the primarily rural state. Yet, the themes discovered may or may not transfer to greater rural Australia and beyond.

In summary, five data collection tools were used in this research project. Some tools were developed by the researcher while others have been used in published research elsewhere. RBNs completed Study Patient Lists, Consultation Logs, and Day Logs, along with participating in semi-structured interviews. Participating

women with breast cancer completed SCNSs at two time points. The next section describes the procedures undertaken.

## **4.5. Procedures**

The aim of this section is to describe where, when and how data was obtained. This is presented in three sections: RBNs, women, and the researcher.

### **4.5.1. Rural Breast Nurses**

A majority of the data collection for this study was completed by RBNs. The researcher provided RBNs with an information sheet and consent form prior to the initiation of data collection. Signed consent signified consent to complete all RBN components of this study. Each participating RBN was given their own RBN code and all research instruments throughout the investigation were marked with this RBN code. Participating RBNs were provided with training on how to complete research tools, invite patient participation, and the procedures for forwarding completed forms to the researcher. RBNs were given instruction from the researcher in how and when to complete the Day Logs, Consultation Logs, and Study Patient Lists, along with eligibility criteria and recruitment of women. Training materials provided are included in at Appendix 8. The RBNs were provided with addressed-paid envelopes to return forms (e.g. client consent forms, and Logs) to the researcher. Participating RBNs assumed the responsibility of recruiting eligible women to the research project.

Day Logs were completed for one full week every month over the 12 month data collection period. One Day Log was used by each RBN for every day worked as a BN during the data collection weeks. RBNs were provided with a list of the weeks of Day Log data collection at the beginning of the study. The researcher prompted the RBNs by email the week prior to remind nurses to complete Day Logs the following week. RBNs posted the completed Logs to the researcher at the end of the week for collection, data imputation, and analysis. The Day Logs were marked with the RBN's code and did not include any other identifying data.

RBNs maintained a list of their clients during the study period in the Study Patient List. The Study Patient List included patient's date of diagnosis, RBN consultations held, a record of invitations to participate and patients' names. Study Patient lists were forwarded to the researcher (excluding patients' names), marked with the RBN's code and no other identifying data, at the conclusion of Phase One. The RBN kept patients' names confidential and these were not forwarded to the investigators. Instead, each client was provided with an individual client code by RBNs. The client code included a link to the client's RBN's code (namely the first letter and number).

Consultation Logs were completed by RBNs for every consultation with participating and non-participating clients during the 12 month Phase One data collection period. The Consultation Logs were marked with the RBN's code, and the client code (from the Study Patient List) and did not include any other identifying data (i.e. names). RBNs forwarded Consultation Logs to the researcher using the provided envelopes every month.

A second information sheet and consent form were given to RBNs prior to Phase Two data collection, as Phase Two was slightly modified from the original research plan. Nurses discussed the care they provided women during semi-structured interviews with the researcher in Phase Two. The interviews were held face-to-face, and arranged by the researcher at a time and location which best suited each individual RBN. Interviews were audio taped with the consent of individual RBNs. No financial remuneration was offered to participants.

#### **4.5.2. Women with Breast Cancer**

Participating RBNs invited eligible women with breast cancer to participate in the research project by providing them with an Information Sheet and Consent Form. Along with signing and dating the form to indicate consent, women were asked to provide their name, address, and date of diagnosis. From this point onwards, all communication to client participants regarding the study came directly from the

researcher. It was anticipated this would minimise the potential conflict of interest that could arise if RBNs were directly involved in their client's participation in the data collection.

Consenting women agreed to complete the SCNS at two time points, one month and three months post-diagnosis. Participants were asked to complete and return the SCNS within a fortnight of their receipt of the survey. An addressed reply envelope returned the survey to the researcher with the client's code and otherwise remained de-identified. No incentives for participation were given.

#### **4.5.3. Researcher**

The researcher coordinated the communication to and participation of the two participant groups, namely women with breast cancer and RBNs. As described earlier, the researcher trained participating RBNs on completing data collection tools and inviting women to participate. Prompts were sent from the researcher to remind RBNs to complete Day Logs during specified data collection weeks. Additionally, the researcher reminded RBNs to return Consultation Logs in pre-paid envelopes monthly, and to forward the Study Patient Lists (with the exclusion of confidential information) at the conclusion of the study.

The researcher maintained a master document to keep track of the distribution and receipt of surveys to and from participating women. The researcher kept a running file on when individual participants were to be sent surveys, and reminder letters if required. Consenting women were sent SCNSs to complete at home at one and three months post-diagnosis. The correspondence included a cover letter, an information sheet, a SCNS and a reply paid envelope. A reminder letter and additional survey were sent if the researcher had not received the survey within the two week deadline. Procedures were consistent with those recommended in the SCNS administration guide (McElduff, et al., 2004). Response aide strategies such as this are evidence-based, diminish response bias, and assist in assuring acceptable response rates and statistical significance to an investigation (Howell et al., 2003).

## **4.6. Analysis**

This section describes the data processing and analysis used in this study.

Furthermore, it explains how missing and overlapping data were handled. Analysis of qualitative and quantitative data was necessary, including descriptive statistics, and thematic analysis. Each data type (quantitative or qualitative) was analysed utilising traditional paradigmatic methods, i.e. it was a non-cross-over mixed analysis. The analysis approaches used by the researcher are described below.

### **4.6.1. Quantitative Data**

The quantitative data sources were imputed into an EXCEL spread sheet by the researcher as a master data document. This included Day Logs, Consultation Logs, Study Patient Lists, and SCNSs. Data entry keys were used for Consultation Logs and SCNSs, but were unnecessary for the Study Patient Lists and Day Logs as the data imputation was straightforward. Separate files were created within Statistical Package for the Social Sciences (SPSS Packages 8 through to 16) to analyse each data collection tool.

Quantitative data from Day Logs, Consultation Logs, and SCNSs were analysed by using simple descriptive statistics within SPSS. The researcher utilised the Study Patient Lists to determine the number of women seen by each RBN, the number and timing of RBN consultations per patient. Day Logs were utilised to describe the amount and proportion of time spent on various RBN duties, while the Consultation Logs were used to analyse the dose, delivery, and content of consultations, typically in the form of means and percentages. For example, dose data were analysed to extract the percentage of clients receiving RBN consultations across the treatment phases, and the mean number of consultations received by clients.

The SCNS was analysed for the prevalence of perceived unmet needs, which is the frequency with which women reported each item to be an area of moderate or high unmet need. Additionally, the prevalence of moderate or high unmet need for access to services were analysed in the same way. The mean number of unmet

needs and the mean number of unmet needs within domains were identified. The relative magnitude of unmet need was compared with other relevant samples whenever possible. Descriptive statistics were sought for the medical and demographic characteristics of the samples. Appropriate tests of statistical significance were sought when applicable. T-tests for paired samples were used for parametric data (i.e. two samples per subject and normally distributed) and non-parametric data were handled with Wilcoxon Signed Ranks Tests for related samples (i.e. two samples per subject while not assuming normally distributed) or Chi squared tests (i.e. two samples per subject while not assuming normally distributed).

Generally speaking, response rates for RBNs and women with breast cancer were well within acceptable levels (Australian Government Statistical Clearing House, 2004). RBN participants demonstrated good adherence to the research protocol and response rates. One hundred percent of Day Logs and Study Patient Lists were returned. However, the completion and return rate of Consultation Logs was unable to be determined as the true number of consultations is unknown. Yet, as 1039 consultations were recorded on Study Patient Lists and 904 Consultations Logs were returned, an approximate 87% response rate for Consultations Logs was received. The response rates of women with breast cancer were also high, with SCNS response rates around 80%.

The researcher was unable to draw direct comparisons of the effectiveness of different RBN sites as the settings and their clients were inherently different<sup>16</sup>. Nonetheless, the thesis provides a comprehensive description of rural breast nursing practices, the influences on these practices, and the extent to which their clients' supportive care needs were met.

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<sup>16</sup> Furthermore, there were insufficient numbers to draw comparisons.

#### **4.6.1.1. Quantitative Analysis Issues**

Two specific analysis issues for consideration in this study are missing data and overlapping data. These have the potential to impact the analysis, results, and decisions about results for presentation. Below is a description of the analysis results which guided decision-making about how to handle missing and overlapping data.

##### **4.6.1.1.1. *Missing Data***

How the missing data was handled has an impact on the analysis undertaken and results received. The researcher was guided by the principles of understanding the data, and ensuring the results were the truest reflection possible of the real world circumstance. "Excluding all cases with missing data can bias the representativeness of the findings, but including such cases by assigning scores to missing data can influence the nature of the findings. The safest and best method is to construct the index using more than one of these methods and see whether you reach the same conclusions using each of the indexes. Understanding your data is the final goal of analysis anyway" (Babbie, 2007, p.164-165).

There was a relatively small amount of missing item data. The missing data is unlikely to challenge the validity of the quantitative analysis results as the response rates were high and the missing data was not found to demonstrate bias. This section describes how missing data was handled. Missing data was considered for Consultations Logs and SCNSs, as these were the only tools where it was possible to identify missing data.

Item non-response, leading to missing data points, affected the SCNS and Consultation Log analysis. SCNSs with missing data were excluded when analysing the prevalence of unmet needs for specific items and overall. Similarly, when data points were missing within Consultations Logs, those Logs were excluded from analysis of individual elements of breast nursing practices. For example, of the 904 Consultation Logs only 853 Logs contained consultation duration data (94% item



response rate, or 6% missing data). Thus the mean consultation duration was analysed using only the available data points (n=853). This was also true for consultation treatment phase (7% missing data, 60 of 904) and face-to-face or telephone (12.5% of all data points were unavailable, 113 of 904). Results with excluded missing data points were compared to those including missing data points, and in general it appeared that the missing data were consistently spread across categories. That is, the analysis results did not vary greatly. Thus, it did not appear that excluding the cases with missing data points would result in an unrepresentative sample, nor make the number insufficient for analysis.

However, a large percentage of missing initiation source data was found in the Consultation Logs (i.e. 41% of all data points were unavailable, 374 of 904). For this reason, initiation source results were presented in terms of the actual percentages that were known. The researcher searched for patterns in initiation source non-response<sup>17</sup>. Reasons for non-response on this item may be due to uncertainty about initiation definitions, perceptions of non-importance or irrelevance, and/or time pressures. Two RBNs in particular had very high non-response rates, 67% and 68%. It is unlikely that the question was challenging for RBN participants, and instead was simply skipped. It may be that some RBNs assumed all consultations would be RBN initiated unless otherwise stated.

#### 4.6.1.1.2. *Overlapping Data*

How overlapping data points were handled could also impact the study results. This was an issue for data indicating the treatment phases during which consultations occurred since it was collected in both Consultation Logs and Study Patient Lists.

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<sup>17</sup> The pattern of initiation source non-response was as follows: decreased over consultation phases, greatest for the *Community RBN Site* (50%) and smallest for *Public/Private Hospital RBN Site* (35%). One *Community RBN* demonstrated the highest non-response with one *Private Hospital RBN* close behind (68% and 67% respectively). The variability in item non-response for initiation source across sites suggests that there may have been many different reasons for non-response.

Thus the analysis of consultation timing was able to be compared across two tools. For instance, Study Patient Lists reported 57% of consultations within specified treatment phases, whereas Consultation Logs described 70% during the same time.

The Study Patient Lists appear to be a more reliable source of consultation timing data as there were 904 Consultation Logs submitted and 1039 consultations recorded within the Study Patient Lists. It was therefore assumed not all consultations were recorded using Consultation Logs, resulting in a discrepancy between the total consultations recorded in the two data sources. The missing Consultation Logs amounted to 13% of the total consultations recorded in Study Patient Lists (i.e. 135 consultations). This obviously had implications on analysis and results using Consultation Logs, which was discussed in the Missing Data section above.

The researcher searched for patterns in non-completion. Direct comparison of the two tools was possible for the number of 'other' consultations and their initiation source. There was a relatively even distribution of missing data between RBN and client-initiated consultations, especially when the missing data was assumed to be RBN-initiated. The total number of 'other' consultations reported via Consultation Logs accounted for only 57% of the total 'other' consultations reported within Study Patient Lists (n=252 and n= 446 respectively). It therefore seems likely that 'other' consultations were those most often excluded from Consultation Log data.

Reasons for Consultation Log non-completion were considered. It is possible the missing Logs were due to procedural issues (e.g. RBNs had consultations and recorded them on the Study Patient List, but no Consultation Log was completed and/or submitted). For instance, an RBN and client may have had an unplanned consultation after they inadvertently met around a cancer service site.

Therefore, Study Patient List data and was used for ratios, percentages, and total numbers of consultations, while Consultation Log data was used for descriptions of breast nursing practices during consultations.

#### **4.6.2. Qualitative Data**

Qualitative data from RBN semi-structured interview transcripts were transcribed by the researcher and a transcriber (whose transcribing was checked by the researcher). Iterative thematic analysis was used to analyse the semi-structured interviews (Braun & Clarke, 2006; Guest et al., 2011; Rubin & Rubin, 1995). Thematic analysis aims to describe the perceptions and experiences of participants through inductive, iterative, content-driven analysis searching for themes (Guest, et al., 2011). Rubin and Rubin describe “when you are done interviewing, you then examine all the interviews together to pull out coherent and consistent descriptions, themes, and theories that speak to your research questions” (Rubin & Rubin, 2005, p.202). This is a well-established qualitative research technique from the interpretive tradition within applied health research. The researcher utilised the RBNs voice to describe breast nursing practices and influences on these practices. The researcher identified important themes, while searching for common threads and underlying ideas, and focusing on the meaning of interviewees (interviewees understandings, and researcher interpretation), and commonalities and diversity of experiences, understandings and breast nursing descriptions.

The role of the researcher was as an interpreter. Data was collected with an open mind, with the analysis aimed at facilitating a process of reflection and discovery. It is important to note however that the researcher assisted in the establishment of two of the three breast nursing sites in a previous professional capacity. Therefore, the researcher had some insights based on her own experiences, readings, and communication with RBNs over a number of years. The researcher considered this familiarity and previous experience as supportive of her research as “people are more willing to talk in depth if they conclude that you are familiar with and sympathetic to their world (Rubin & Rubin, 1995, p.76).” Thus, she was familiar with the issues and vocabulary, as well as the informants themselves. Additionally, interviewees were aware of the researcher’s supportive attitude toward the interviewee's work and efforts.

Nonetheless, the qualitative analysis was guided by the data. Data was sifted into themed areas. Common elements or conceptual themes were identified and grouped to discern patterns within the data. Thus, a typical iterative qualitative process was undertaken. The researcher “let ideas emerge from the interviews, from the lives and examples of the interviewees, rather than to categorize answers initially according to pre-existing categories from an academic literature” (Rubin & Rubin, 1995, p.38). Using iterative thematic analysis the researcher allowed themes to arise from the data inductively, being guided by the data set, then searched the theoretical literature for pre-existing concepts which reflected the patterns which were emerging.

“In qualitative interviewing, theories emerge from the interviews” (Rubin & Rubin, 1995, p.68). The researcher reflected on her first analysis of the interviews, and looked for a conceptual framework within the literature which matched her findings. Once the framework was identified, the researcher returned to the data analysis and was able to extend the generic nursing framework with new learnings. Semi-structured interviews were then analysed within the aforementioned generic nursing conceptual intervention framework, with the researcher identifying intervention, intervener, client, and setting characteristics influencing nursing practices and client outcomes. Additionally, breast nursing practices were described utilising the RBNs’ own words and examples. The qualitative analysis was done with pen and paper, with findings summarised in MS Word documents, and reported in Chapters Seven and Eight.

#### **4.6.3. Integration of Quantitative and Qualitative**

The final analysis included an integration of quantitative results and qualitative findings. Mixed methods integration was described within the Rationale for Mixed Methods in Pragmatism section on page 71. This entailed linking inference strands from the different components of the study. These were then considered in light of the generic nursing conceptual intervention framework (Sidani & Braden, 1998) and

the wider literature. The resulting meta-inferences enabled the development of the conceptual framework for breast nurses' practice in rural settings.

## **4.7. Ethical Considerations**

The principles of ethical conduct guided the research processes. Ethical issues of concern related to women with breast cancer, RBNs, and the researcher were considered. The researcher maintained integrity with the support of experienced supervisors. The research was designed with a commitment to knowledge, honesty, and truth, whilst utilising appropriate research methods. Additionally, the basic ethical principles of respect for persons, beneficence, and justice were considered (National Health and Medical Research Council, 1999).

Respect for persons was enacted by providing individuals with an opportunity to decide whether to participate or not within the information sheets and consent forms. Additionally, RBNs were asked to use their discretion about whether their clients should not be invited due to their physical, mental, or personal status, thereby protecting those with diminished capacity to decide. Women with breast cancer were also invited to revoke consent with each survey sent. Maintaining RBNs' confidentiality provided challenges, and steps were taken to mask individual's identity. To protect individual RBNs, some results were not reported to hide RBNs' identity (i.e. withheld to protect the confidentiality of RBNs).

The researcher shaped the research question and methods to ensure beneficence, i.e. to minimise possible harms and maximise possible benefits for participants. The researcher set out to minimise any potential additional distress caused by study participation, by for example having RBNs invite clients. Also, the researcher attempted to minimise the additional research workload to RBNs (e.g. ensuring consultation logs would be useful to their clinical practice). Furthermore, the researcher demonstrates sensitivity to the rights and interests of potential participants by using the results to better the experience for others into the future, including women with breast cancer and those caring for them.

The ethical principle of justice led the researcher to broadly distribute the benefits of the study, as well as the burden of participation. Specifically, both public and private clients and RBNs were included across the full state. Additionally, this research will bring benefit to rural health services which have been underrepresented in previous Australian breast nurse research (a Tasmanian site was not included in the NBCC SBN Demonstration Project, nor were regional areas proportionally represented in the investigation).

An ethics application was granted by the Southern Tasmania Health and Medical Human Research Ethics Committee in April 2003 (Ethics Reference # H0007203)<sup>18</sup>. This body represents a state-wide ethics committee for health research within the University of Tasmania and public hospitals. Ethics approval was also granted from the two Private Hospital sites through their independent ethics committees. Meanwhile the other sites deferred to the Tasmanian Medical Ethics Committee's decision. Information and consent forms were provided to all participants, including RBNs and women with breast cancer (as discussed in the Procedures section). Ethics progress reports were completed as required throughout the research project.

Ethics committees had previously accepted two of the research tools, Day Logs and SCNSs. The Day Logs were used within the NBCC SBN Demonstration Project and were only slightly modified for this study. The SCNS was previously approved by ethics committees for multiple uses by the Cancer Education Research Program of The Cancer Council New South Wales and other groups.

Appropriate steps were taken to maintain the confidentiality of all participants. The hard copies of data collected have been stored in locked filing cabinets within the

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<sup>18</sup> An ethics amendment application was accepted in September 2006 by the Human Research Ethics Committee (Tasmania) Network. The amendment addressed a modification to Phase Two data collection methods, and included an updated information sheet and consent form for RBNs.

University of Tasmania. The researcher's computer containing the data has been password locked. Additionally, data contains RBN and client codes rather than names, with the exception of interview transcripts. Furthermore, there are several instances where findings have not been linked to RBN sites to maintain the confidentiality of participants.

## **4.8. Limitations and Weaknesses**

There are limitations and weakness to this research project, as there are to any research undertaken. The study can be considered an ecologically valid research setting as it was set within real world conditions. Yet threats to the legitimisation of the data and inferences still exist<sup>19</sup>. This section describes the limitations and weaknesses of the research design, namely the threats to inference quality and inference transferability, and thus the study's legitimisation.

### **4.8.1. Inference Quality Threats**

Inference quality is the mixed methods term relating to quantitative research's 'internal validity' and qualitative research's 'credibility'. Possible threats to the inference quality of this study include selection bias, differential attribution, experimenter bias, and the reliance on self-report. This section discusses the inference quality concerns for this study.

Selection bias is a possible threat to inference quality. Selection bias was not a threat for the RBNs as all RBNs in the sample agreed to participate. However, there was likely a selection bias in relation to participating women with breast cancer. It is possible RBNs did not invite some clients to participate, for example extremely distressed or elderly women. It may also be that women who had initially agreed to

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<sup>19</sup> The overall term reflecting the quality of mixed methods research is legitimisation, which echoes quantitative research's 'validity' term and qualitative research's 'trustworthiness' term.

participate chose not to return their surveys when they experienced difficulties later. Other SCNS studies would have likely faced the same challenges.

In this study response rates amongst consenting women with breast cancer were relatively high (83% and 78% respectively), yet less than 30% of all possible – although not necessarily eligible - women participated. That is, RBNs consulted with 239 women during the study period with 74 and 83 returning SCNS at each time points. The number of women turning down an invitation to participate is not known, nor is the number that nurses did not to invite. Additionally the number of women who may have been ineligible is not known (e.g. consulting with RBN after the specified data collection points).

This study was dependent on RBNs to recruit client participants. There are inevitably limitations of relying on healthcare staff for recruitment to research projects. Although RBNs expressed willingness to recruit client participants, this can be difficult in the context of a busy practice, as noted in other studies (Soothill et al., 2004). Thus, there were challenges in accessing client participants. For example, RBNs reported varied degrees of comfort and 'success' in gaining consent.

Differential attrition was another possible threat to inference quality in this study. Some clients did not follow through on their agreement to participate i.e. they did not return surveys. It could have been that woman who had initially agreed to participate did not complete surveys (and/or dropped out) as they were not coping well, whereas those who were coping well did return surveys. However, other SCNS studies would have experienced similar challenges.

Attrition may have also been an issue for RBNs. While not dropping out of the study, it is possible that completion rates of Study Patient Lists and Consultation Logs were less than complete. Although this was not the case with Day Logs (100% return rate), the researcher was unable to quantify the amount of missing Consultation Logs and Study Patient Lists. As identified above, missing data undoubtedly existed (e.g. at least 13% of consultations went unrecorded in



Consultations Logs as opposed to Study Patient Lists), but the extent of missing Consultation Logs (and/or data points on Study Patient Lists) is unknown.

Experimenter bias is also a possible threat to inference quality in this study. The researcher's perspective impacted what was studied, how it was studied, and the results of data analysis attained in the qualitative strand as well as the integration of quantitative and qualitative results to meta-inferences. The researcher's background and experiences outside of nursing, though in supportive cancer care systems, meant she may have had different insights than another researcher with another background. Furthermore, the researcher's previous work with these interview informants could have had an impact on what, and the extent to which, RBNs chose to share. This is recognised as a potential bias. Yet, at most, only a minimal power relationship existed between researcher and researched at time of interview. As the researcher was familiar with the RBNs and generally with the health systems in which they functioned, it is likely that objectivity was not possible. On the other hand, insights might have been gained as the researcher had intimate knowledge of individuals and systems, and had discussed challenges with RBNs previously.

The research inferences benefited from the researcher's knowledge of the nurse participants and contexts in which they worked. "A golden rule of making inferences in human research is *know thy participants*! Having a solid understanding of the cultures of the participants and the research context is a valuable asset in the process of making inferences" (Teddlie & Tashakkori, 2009, p.289). These understandings and knowledge assisted the researcher to interpret the results.

Another component of inference quality that poses threats to this study is the reliance on self-report. The heavy reliance on accurate self-reporting is an important limitation of this study. The SCNS relies solely on patients' self-report, with no assurance of the accuracy of these reports. Similarly, Day Logs, Consultation Logs, and Study Patient Lists rely on RBNs accurate recordings. It is possible that the data was inaccurate as all of the quantitative research tools relied

on self-report. Women with breast cancer may have positively framed their responses in an effort to ensure RBNs received positive feedback, as women consulting BNs have generally been very supportive of them. It is also possible participating RBNs reports were skewed in order to positively frame their breast nursing practices.

With regards to SCNS self-reports, there are inherent challenges around individuals completing health need questionnaires. "Health needs is a deceptively tricky concept" which requires a "concise, valid and reliable tool" for evaluation (Asadi-Lari & Gray, 2005, p.294). Self-administered questionnaires are less expensive and intrusive than interviews, easily distributed and allow participants to complete them in their own time (Asadi-Lari & Gray, 2005). Yet self-administered questionnaires can lead to misunderstandings and or superficial investigations with imprecise wording and limited interactions with participants (Asadi-Lari & Gray, 2005). Thus checks of validity and reliability are essential.

Although the SCNS tool was validated by its developers (Bonevski, et al., 2000), there were difficulties with this data collection tool identified by the researcher and RBNs in this study. For example, it was clear there was misunderstanding that surgery is considered a form of 'treatment' based on the inconsistent replies of women. Additionally, more than one nurse reported they believed women would misunderstand the scaling. Instead, RBNs suggested women would consider the numbers 1 – 5 reflecting intensity rather than truly considering the 'satisfied' component of the scale. Others have reported similar concerns with the SCNS scale<sup>20</sup>.

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<sup>20</sup> In June 2004, Ms Alison Zucca of the Centre for Health Research & Psycho-oncology reported respondents having problems with the complexity of scale while noting it had been 10 years since the SCNS's validation during a presentation at the Behavioural Research in Cancer Control Conference.

Furthermore, it can be challenging to understand the meaning of SCNS results. The results can often only be understood in relation to with other results using the same instrument. Thus baseline or reference data is important<sup>21</sup>. Therefore, comparisons have been made to other studies to add greater meaning to the SCNS results within this study.

#### **4.8.2. Inference Transferability Threats**

Inference transferability is the mixed methods term relating to quantitative research's 'external validity' and qualitative research's 'transferability'. Inference transferability threats arise when researchers draw incorrect inferences from one study to other samples, settings, and/or situations (Creswell, 2003). Threats to the inference transferability of this study include the effect of other factors on the outcomes, the Hawthorne effect, and the generalisability of findings. This section details the inference transferability concerns for this study.

One cannot assume the outcomes reported by women in this study are only due to the RBN services, nor the RBN in conjunction with the broader healthcare team. This investigation does not assess the impact of breast nursing practices in isolation from other services or socio-cultural experiences. Other factors will undoubtedly support or detract from women's experience and outcomes. For example, mental health outcomes of older women with breast cancer are mitigated by the perception of family support (Maly et al., 2005). Therefore clients' outcomes in this study could be due to family support rather the RBN and/or other health services. This thesis attempts to address the issue that rural breast nursing practices and client outcomes are influenced by other factors (namely clients, socio-cultural and physical contexts, and interveners). Thus, the researcher has attempted to make

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<sup>21</sup> This is similar for quality of life data, where sub-group results are compared to baseline data for a broad healthy population.

transparent the many direct or indirect influences on outcomes for women with breast cancer which are often beyond the control of BNs.

The potential effects of the awareness of being studied could threaten the inference transferability of the findings. The Hawthorne effect (i.e. the knowledge of being studied) may have had an effect on the nursing practices, records, and responses of RBNs as well as on their clients'. As mentioned earlier, women might tailor their responses to reflect positively on RBN services. The literature highlights that the conditions in which participants are questioned can affect the narrative portrayed by subjects (Pierret, 2003). Furthermore, the narrative portrayed may follow the line that subjects believe the interviewer might be interested rather than their predominant experiences (Lawton, 2003). This threat to women's responses was mitigated in two ways: by SCNSs being posted directly to women at home; and the correspondence originating from the researcher rather than RBNs.

The transferability of results to other sites is obviously an important and relevant question. Although the study was comprehensive, it contained relatively small sample sizes confined to a specified area and timeframe in primarily rural Australia. This makes the generalisability of quantitative results difficult. This is counterbalanced with the strengths of the qualitative strand. The interviews added strength to the findings as "the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than the sample size" (Patton, 2002, p.245). Together the quantitative and qualitative strands build meta-inferences leading to the development of the conceptual framework for breast nurses' practices in rural settings. This is where this thesis' transferability strength lies.

One final threat to the inference transferability is the reliance of data on relatively new RBNs and roles. Importantly, four of the five RBNs participating in Phase One were newly implemented within the 6 months preceding the study. These RBNs may have spent time setting up their services which would have impacted their

time distribution across duties. For example, possibly more time was spent promoting and explaining their role. Furthermore, RBNs in this study described consulting with individuals who were beyond early breast cancer (e.g. recurring disease), as well as those with other cancers. This was confirmed in RBN interviews. This has the potential to affect the findings in relation to RBNs overall distribution of time.

The lack of a focussed breast nursing for women with early breast cancer might negatively impact the inference quality. However, it could be that this expanded scope of breast nursing practices increases the generalizability of the results as working with a wider set of clients is quite possibly a usual - although unstated - duty of BNs. For example, consulting with clients beyond the usual brief was identified within the NBCC SBN Demonstration Project (SBN Project Team 2000). However, it is not known the extent to which this was the case for RBN sites as there was no means to capture this information within this study.

## **4.9. Chapter Summary**

This chapter has detailed the methodology and methods of this research project. The features of pragmatism were described and related to this thesis, the rationale for mixed methods use, and criticisms of pragmatism and mixed methods, as well as the use and acceptance of mixed methods. The generic nursing theory-driven conceptual intervention framework was explained as it relates to this thesis. The research design was described and the sample and setting, tools, procedures, analysis, and ethical considerations presented. The limitations and weaknesses were presented, along with a means to judge the quality of the design and interpretations.

This thesis fits within the pragmatic tradition as it is practically oriented toward improvements to real world practice. The value of improving women's experiences with breast cancer is explicitly stated, and the impact of context is acknowledged and explored. The research is undertaken in the naturalistic setting rather than

being experimental. The research questions draw from the theory-driven conceptual framework to determine what factors are important in shaping rural breast nursing practices, and how these factors influence nursing practices and client outcomes.

A sequential explanatory design was utilised. The study begins with broad quantitative surveys of breast nursing practices and outcomes for women, and then narrows in on why RBNs worked in the ways they have through semi-structured interviews. Three RBN sites are described with seven RBNs participating in the quantitative data collection and six participating in the qualitative strand. All RBNs employed in the role during the two data collection periods participated in the study.

Women with breast cancer and RBNs formed the two sample populations. A whole of population recruitment strategy was undertaken, with purposive sampling including all RBNs and all eligible women consulting them. RBNs recruited eligible clients to the study. Women with breast cancer consulting RBNs completed SCNS at two time points, one and three months post-diagnosis. RBNs completed Day Logs, Consultation Logs, and Study Patient Lists. Additionally, RBNs participated in semi-structured interviews as part of the qualitative Phase Two strand. Each type of data was analysed according to its original paradigmatic perspective. Quantitative data was analysed within SPSS for descriptive statistics. Techniques for handling missing and overlapping data were described. Qualitative data was analysed used thematic analysis.

The limitations and weaknesses of the methodological approach and the design of this study were explored. Threats to legitimation including the inference quality and inference transferability were identified and a framework from which to judge the quality of the thesis was presented. The ethical considerations were assessed and risk mitigated during all research processes.

The following chapters present the findings arising from the methodology and methods described in this and the previous chapters. Specifically, Chapter Five presents clients' unmet supportive care needs with the analysis results of the SCNS and comparisons to other studies. Chapter Six describes rural breast nursing practices through the analysis results of Day Logs, Consultation Logs, and Study Patient Lists. Chapters Seven and Eight present RBNs' insights on nursing practices based on the analysis of semi-structured interviews. Furthermore, these results provide the building blocks of the conceptual framework for breast nurses' practice in rural settings presented in Chapter Nine.

## **Chapter Five: Supportive Care**

### **Outcomes of RBN Clients - unmet needs and changes through time**

This chapter details the outcomes for women consulting an RBN, and sheds light on the client characteristics which influence these outcomes. As shown in the preceding chapters, breast nursing aims to improve the journey of women with breast cancer through the provision of supportive care. RBNs work to prevent, resolve, and/or manage adverse outcomes for women, in concert with wider cancer care systems. Breast nursing practices aim to relieve the burden of disease on the person's quality of life through minimising unmet supportive care needs (e.g. physical, mental, and social well-being). The intended outcome for women is an improved journey with breast cancer, operationalised in this study as women's supportive care needs.

Previous studies have identified predictors of high unmet needs from their samples. While predictors of unmet need were not sought in this study, they are presented here for reference. Higher needs and/or the reporting of some needs have been associated with advanced disease (Foot & Sanson-Fisher, 1995), recent or active treatment (Carlson & Bultz, 2004; Girgis, et al., 2000), young age (Carlson & Bultz, 2004; Soothill, et al., 2004; Soothill et al., 2001), and female gender (Carlson & Bultz, 2004; Sanson-Fisher, et al., 2000; Soothill, et al., 2004). Predictors of need have often been found to vary according to the need domain (Girgis, et al., 2000; Sanson-Fisher, et al., 2000; Steginga, et al., 2001). For instance, rurality was a predictor of Physical and Daily Living Domain needs (Girgis, et al., 2000). Lower unmet needs have been associated with remission (Foot & Sanson-Fisher, 1995). The respondents who formed the samples of this study met some of the criteria for predictors of need, namely female, active treatment, and the vast majority would



have been classified as rural. Thus, based on previous identified predictors of unmet supportive care needs, the samples within this study would be expected to have greater than average high unmet needs.

Breast nursing practices aims to facilitate women's supportive care needs being met, thereby diminishing unmet supportive care needs and enhancing women's health status. Multiple data collection points were warranted as RBN involvement is intended to be over a significant period of time and women's needs are understood to change over time. The prevalence of high unmet needs is used as the proxy for measuring the effectiveness of breast nursing practices, in conjunction with the broader health and supportive care systems and contexts<sup>22</sup>. By comparing these results with those of other samples, the relative quality of their cancer journey can be better understood. Therefore, this chapter answers the sub-question: *To what extent are women consulting RBNs having their supportive care needs met?*

The results are drawn from the analysis of the SCNS, as previously described in Chapter Three. To summarise, surveys were posted one and three months post-diagnosis to consenting RBN clients meeting eligibility criteria. Scoring and analysis were undertaken as per recommendations in the SCNS guide to administration, scoring and analysis (McElduff, et al., 2004). The need items were categorised into domains as per the guide, namely Psychological, Physical and Daily Living, Sexuality, Patient Care and Support, and Health System and Information Domains.

Client characteristics are important as they have the potential to influence outcomes for women. More specifically, client characteristics can shape one's response to disease, their presenting problems, the treatment undertaken, and the response(s) to treatment, all of which ultimately influence the outcomes. The client

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<sup>22</sup> For simplicity within this chapter, moderate to high unmet supportive care needs are referred to as 'high unmet needs'.

characteristics which potentially influenced outcomes include personal, health, and resource factors (Sidani & Braden, 1998) and were collected with the survey as the personal and medical characteristics of the samples. The personal factors presented are demographic information, namely gender and age, while the resource factor collected was marital status. The health factors presented are the medical characteristics relating to cancer treatments received and the cancer remission status. These health factors assist in describing the disease circumstances that women were facing at the time.

The results describe which supportive care needs are not met by the RBN and/or the healthcare system, and thus remain a high unmet need for women. This information provides a clear picture of the persistent issues for women with breast cancer, and which issues are most problematic at which times. The results also clarify the similarities and differences between high unmet needs for this sample in comparison to other samples. Furthermore, the client characteristics provide an image of the women's personal, health and resource factors which potentially influenced outcomes.

These quantitative results are linked within the thesis to the other results chapters. Specifically, these findings are linked with the objective characteristics of breast nursing practices (Chapter Six), and RBNs' description of breast nursing practices and factors influencing nursing practices (Chapters Seven and Eight). Together, these results highlight which factors influence breast nursing practices and how these factors exert their influence on nursing practices and the supportive care outcomes of their clients (Chapter Nine).

The study settings are first presented in this chapter. Then the prevalence of unmet needs, their changes over time, as well as comparisons with relevant studies are presented. The comparisons of results with other studies provide a picture of relative experiences within the cancer journey. Unmet needs for access to services are also explored.

These findings are reported in four sections of this chapter. Firstly the Time One and Time Two results are described separately in terms of sample characteristics, prevalence of high unmet need generally and access to services. Then the changes and patterns of high unmet needs over time are explored. Finally, the results of this study are compared to previous studies utilising the SCNS or its predecessor.

## **5.1. Study Settings - RBN Services and Sites**

Three RBN services are described in this thesis. The RBN services varied greatly in their organisational parameters and regional cancer settings. The services described include a newly implemented service comprising two private hospital positions (*Private Hospital RBN Site*), one ongoing North RBN service comprising one position working across the public and private hospitals (*Public/Private Hospital RBN Site*), and one RBN service being piloted with two community-based positions (*Community RBN Site*). The RBN services' organisational parameters and regional healthcare settings are described in this section.

The *Private Hospital RBNs* in one region were 'add-on's to other positions, namely a discharge planning nurse and a nurse who primarily worked on the surgical ward. These nurses were given limited additional hours to undertake their new roles, and were primarily restricted to the hospital setting. The region contained one public hospital, where all radiotherapy and chemotherapy services were provided to public and private clients, and two private hospitals where breast surgeries were undertaken. Clinicians (i.e. surgeons and oncologists) did not specialise in breast cancer specifically, nor was there a specific cancer clinic in the region. No public psychologists were available for referral, while a social worker was available through the public hospital oncology wards. All hospitals are located within the main regional city. Approximately 3 surgeons, 4 radiation oncologists, and 4 chemotherapy oncologists serviced the region.

The *Community RBNs* in another region were clearly defined roles new to the community setting. Two part-time positions worked together to service the region

(e.g. providing holiday cover and support), with the ability to move across both the public–private and hospital–community divides. The community breast nurses brought experience, knowledge, and connections from the surgical and oncology wards, as well as palliative and community care, giving them great breadth and depth in understanding and professional linkages or contacts. Two private hospitals provided breast surgical services, as did the public hospital. The public hospital provided all chemotherapy and radiotherapy services, with the support of an oncology social worker. A psychologist had limited availability for public clients. No specialist clinicians dealt solely with breast cancer, nor was there a cancer clinic. Approximately five main surgeons, three radiation oncologists, and five chemotherapy oncologists serviced the region.

The *Public/Private RBN* worked in a full time position where she served as both a BCN and Stomal Therapy Nurse in an established position (over 10 years previous to quantitative data collection) that primarily serviced two hospitals (public and private) which sit directly next to one another (i.e. same parking lot), with many health service providers working between the two. The RBN, though funded through the public system, was allowed access across the public-private divide yet largely hospital setting focussed. Surgical services were provided in both public and private settings, and chemotherapy was only in the public setting. Accessing radiotherapy services for these clients necessitated travelling to another region (2.5 hr. drive between hospitals). This region represented the most rural and remote of those in this study with some clients travelling significant distances for care (e.g. 4 hrs.). A social worker was available through the public system, and psychological services were sparse if any in the private setting. Approximately 2 surgeons, 1 radiation oncologist, and 2 chemotherapy oncologists serviced the region.

The RBN services have been described above in their organisational context, yet not all sites were contained in a traditionally understood 'site' working together to serve the needs of their constituents. Specifically the *Private Hospital RBN Site*,

although referred to as singular, was more correctly made up of two sites servicing two separate private hospitals.

## **5.2. One Month Post-Diagnosis (Time One)**

This section presents women's unmet needs at one month post-diagnosis, including the demographic and medical characteristics of those who participated. One-hundred and seven eligible women agreed to participate in the survey. Of these, 89 women were surveyed at one month post-diagnosis with 74 surveys returned (83% response rate). The following sections contain the sample characteristics and the prevalence of high unmet needs and unmet needs for access to services at time one.

### **5.2.1. Sample - Time One**

The sample's demographic and medical characteristics can be important in understanding the personal and patient attributes which may affect their needs. Sample characteristics are presented as either relatively stable features defining a respondent (i.e. personal and resource factors), or characteristics which defined the woman's present point in her breast cancer journey (i.e. health factors). The sample's personal, resource, and health characteristics are presented in Table 3.

The demographic (i.e. relatively stable) characteristics of respondents illustrated the type of person who participated in the survey. Marital status is considered a resource factor as it may influence social support and financial status for example. Age and gender (all female in this study) are personal characteristics. Time One respondents were primarily married or living with a partner (74%), and aged 41 – 70 years (81%), while 51% were between 51 and 70 years of age. The age profile was generally consistent with cancer registry data although participants in this study were younger than the registry average (Newman, et al., 2006), as presented in Sample and Setting section of the previous chapter.

The sample's medical characteristics distinguished the respondent's stage in the cancer journey, and helped to illuminate what was happening medically for these women (i.e. health factors). Almost all respondents had surgical removal of cancer in the last month (94%). These women typically were first told of their cancer in the preceding three months, with almost a quarter having been told in the last month. Almost half understood their cancer was in remission. Of note, 33% of respondents at one month post-diagnosis did not know if their cancer was in remission or not.

**Table 3: Demographic and medical characteristics of the respondents at one month post-diagnosis (T1)**

QUESTION	RESPONSE	One month post-diagnosis (n=74)
Age (years)	31-40	4%
	41-50	30%
	51-60	25%
	61-70	26%
	>70	15%
Married / living with partner	Yes	74%
	No	26%
Cancer treatments received <i>ever</i>	surgery	97%
	chemotherapy	41%
	radiotherapy	35%
	hormone treatment	31%
	immunotherapy (injection)	0%
	other	6%
First told of cancer	within the last month	24%
	1-3 months ago	62%
	3-6 months ago	5%
	> 6 months ago	8%
Remission	No	20%
	Yes	47%
	don't know	33%
Cancer treatments received <i>in the last month</i>	surgery	94%
	chemotherapy	29%
	radiotherapy	7%
	hormone treatment	19%
	other	9%
Most recent hospital treatment for cancer	within the last month	78%
	1-3 months ago	20%
	3-6 months ago	0%
	6-12 months ago	0%
	>12 months ago	0%
	never	3%

Interesting differences arose between cancer treatments received ‘ever’ versus those ‘received in the last month’. Many more respondents reported having

received chemotherapy, radiotherapy, and hormone treatment 'ever' (41%, 35%, and 31% respectively) than those reporting having received these cancer treatment in the past month (with 29%, 7%, and 19% respectively). These findings suggest some women were receiving other cancer treatments prior to surgical treatment, which diverges from previous standard procedure (i.e. surgery followed by other cancer treatment(s)). For example, 35% reported they had radiotherapy treatment, while only 7% stated they had radiotherapy treatment in the last month. This may be due to standard practice changing to multiple practices dependant on the diagnostic particulars of the cancer (e.g. traditionally radiotherapy is after surgery). Alternatively, these findings could also be due to this breast cancer diagnosis being a second cancer diagnosis, and/or participants responding outside of agreed survey timeframes.

It should be noted RBNs provided a date of diagnosis for each participating woman, and the researcher distributed surveys using this date as a guide. However, some participants reported their diagnosis outside of the agreed timeframes (i.e. one month or three months post-diagnosis). For example, 13% of time one respondents reported they had first been told of their cancer more than three months previously.

### **5.2.2. Prevalence of Unmet Needs - Time One**

Outcomes for women were operationalised in this study as the prevalence of high unmet needs. The percentage of respondents reporting high unmet needs indicates the prevalence of perceived unmet supportive care needs. Importantly, more than one-third of respondents reported no high unmet needs at one month post-diagnosis. The mean number of high unmet needs at one month post-diagnosis was 8.3 out of 59 possible items.

At one month post-diagnosis, twelve SCNS items had equal or greater than 20% of respondents reporting high unmet needs (i.e. one in five). The top seven high unmet needs at one month post-diagnosis were from the Psychological domain.



The top ten unmet needs also included two from the Health System and Information, and one from the Physical and Daily Living domains. A full table listing the prevalence of high unmet needs for all items at one month post-diagnosis is available at Appendix 10. Those items most often reported as high unmet needs were ‘concerns about the worries of those closest to you’ (40%), ‘fears about cancer spreading’ (35%), ‘fears about the cancer returning’ (32%), and ‘anxiety about having treatment’ (30%). The top high unmet needs at one month post-diagnosis are ranked in Table 4, including the respective domains for each item.

**Table 4: Most prevalent (top 15) high unmet needs reported at one month (T1) post-diagnosis (n=74)**

RANK	ITEM	T1	DOMAIN
1	concerns about the worries of those closest to you	40% (29)	Psychological
2	fears about cancer spreading	35% (26)	Psychological
3	fears about the cancer returning	32% (23)	Psychological
4	anxiety about having any treatment	30% (22)	Psychological
5	uncertainty about the future	29% (21)	Psychological
6	worry that the results of treatment are beyond your control	27% (20)	Psychological
7	changes to your usual routine and lifestyle	26% (19)	Psychological
8	being informed about things you can do to help yourself get well	23% (17)	Health System / Information
9	being adequately informed about the benefits and side-effects of treatments before you choose to have them	22% (16)	Health System / Information
9	lack of energy or tiredness	22% (16)	Physical / daily living
11	concerns about the ability of those close to you to cope with care for you	20% (15)	Psychological
11	being informed about your test results as soon as feasible	20% (15)	Health System / Information
12	not being able to do the things you used to do	19% (14)	Physical / daily living
12	feelings about death and dying	19% (14)	Psychological
12	anxiety	19% (14)	Psychological
12	talking to other people about the cancer	19% (14)	no domain

These findings reflect the heavy psychological burden of the health and disease circumstances women were dealing with at one month post-diagnosis. The results are consistent with the recent diagnosis and the beginning of treatment (as per the medical characteristic identified in the previous section), and suggest that fears and concerns still remain for women at this early stage.

### 5.2.3. Access to Services - Time One

Access to supportive services potentially diminishes the prevalence of high unmet needs. Respondents' reported high unmet needs for access to services at one month post-diagnosis are presented in this section. The majority of respondents did not have any high unmet needs for access to services at one month post-diagnosis (60%). Nineteen percent of respondents reported needing access to one service at one month post-diagnosis. When comparing access to services across sites at Time One, participants from the *Private Hospital RBN Site* reported the greatest high unmet needs, while participants from the *Community RBN Site* reported the fewest. Table 5 presents the percentage of respondents in descending order reporting high unmet needs for specific access to services at one month post-diagnosis.

**Table 5: Percentage of high unmet needs reported for access to services at one month post-diagnosis (T1)**

SERVICE	T1
easy parking at the hospital or clinic	23%
relaxation classes	10%
24-hour telephone support and cancer advisory service	9%
brochures about services and benefits for patients with cancer	8%
monetary allowance for travel, treatment and equipment expenses	7%
library of books and videos about cancer and related issues	7%
home cleaning service	7%
drop-in counselling and support service	6%
home gardening service	6%
counselling services (e.g. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family / partner	5%
transport service to and from the hospital or clinic	4%
food and drink facilities in or near the clinic waiting room	3%
home nursing service	1%
comfortable waiting area	1%
respite care	0%
child-minding at the hospital or clinic	0%

The high unmet need most often reported for better access to services at one month post-diagnosis was for 'easy parking at the hospital or clinic' (23%). Other

high unmet service access needs were reported by 10% or less of respondents. The results indicate the practical need for ease of parking to access treatment or consultations posed significant issues for almost a quarter of respondents. Nonetheless, these findings suggest respondents generally had access to the services they required, with the exception of easy parking.

In summary, respondents at one month post-diagnosis were primarily married or partnered, and aged 41 – 70 years. Respondents typically had undergone surgery in the last month, and had learned of their cancer within the last 3 months. The sample had a relatively similar demographic profile to that of the cancer registry. Although much of the sample's health journey appeared typical of the early breast cancer experience, a few women reportedly undertook other forms of cancer treatment before surgical intervention. These findings give insight into who participated, and what they were experiencing in their breast cancer journey. These personal and medical characteristics have the potential to influence outcomes for women.

The most prevalent high unmet needs at one month post-diagnosis were dominated by the Psychological domain and typically related to concerns, fears, worries, uncertainties and anxieties. These findings echo the psychological challenges inherent in a recent diagnosis and treatment for a life-threatening illness. Time One respondents generally reported favourably regarding their access to services, other than easy parking.

### **5.3. Three Months Post-Diagnosis (Time Two)**

One hundred and seven women were surveyed at three months post-diagnosis, with 83 surveys returned (78%). Seven women withdrew from the study. This section presents the sample characteristics, prevalence of high unmet needs, and access to services for respondents at three months post-diagnosis.

### **5.3.1. Sample - Time Two**

The demographic and medical characteristics of the three months post-diagnosis respondents are reported in this section and are presented in Table 6. The respondents at three months post-diagnosis were primarily married or living with a partner (71%), and aged 41 – 70 years (83%), while 61% were between 41 and 60 years old. Time Two respondents were primarily told of their cancer 1 – 6 months previously, about half were told their cancer was in remission, and 70% had received their most recent cancer treatment in hospital within the last month. Of the cancer treatments received in the last month, most received chemotherapy, and then hormone treatment followed by radiotherapy. Notably, 16% of respondents had cancer surgery in the last month. Thirty percent of the time two respondents reportedly knew their cancer was not in remission, while 16% did not know the cancer's status.

**Table 6: Demographic and medical characteristics of respondents at three months post-diagnosis (T2)**

QUESTION	RESPONSE	Three months post-diagnosis (n=83)
Age (years)	31-40	5%
	41-50	30%
	51-60	31%
	61-70	21%
	>70	13%
Married / living with partner	Yes	71%
	No	29%
Cancer treatments received <i>ever</i>	surgery	96%
	chemotherapy	71%
	radiotherapy	38%
	hormone treatment	46%
	immunotherapy (injection)	9%
	other	0%
First told of cancer	within the last month	1%
	1-3 months ago	39%
	3-6 months ago	57%
	> 6 months ago	2%
Remission	No	30%
	Yes	53%
	don't know	16%
Cancer treatments received <i>in the last month</i>	surgery	16%
	chemotherapy	63%
	radiotherapy	24%
	hormone treatment	36%
	other	10%
Most recent hospital treatment for cancer	within the last month	70%
	1-3 months ago	17%
	3-6 months ago	8%
	6-12 months ago	1%
	>12 months ago	0%
	never	4%

### **5.3.2. Prevalence of Unmet Needs - Time Two**

The prevalence of high unmet needs reported by respondents at three months post-diagnosis is presented in this section. Importantly, a substantial percentage of respondents reported no high unmet needs at three months post-diagnosis (41%). The mean number of high unmet needs at three months post-diagnosis was 7.7 out of 59 possible items. A full table listing the prevalence of high unmet needs for all items at three months post-diagnosis is available at Appendix 10. The top unmet needs at three months post-diagnosis are ranked in Table 7, along with the domains associated with each.

At three months post-diagnosis, fourteen questions had equal or greater than 20% of respondents reporting high unmet needs (i.e. one in five). Half of the top ten high unmet needs were from the Physical and Daily Living domain, and four were of the Psychological domain. 'Lack of energy or tiredness' was reported as being a high unmet need by approximately one in three respondents at three months post-diagnosis and was the most prevalent high unmet need at time two.

**Table 7: Most prevalent (top 15) high unmet needs reported at three months (T2) post-diagnosis (n=83)**

RANK	ITEM	T2	DOMAIN
1	lack of energy or tiredness	31% (25)	Physical / daily living
2	not sleeping well	26% (21)	Physical / daily living
2	anxiety about having any treatment	26% (21)	Psychological
4	not being able to do the things you used to do	24% (20)	Physical / daily living
5	fears about cancer spreading	22% (18)	Psychological
5	fears about the cancer returning	22% (18)	Psychological
7	work around the home	21% (17)	Physical / daily living
7	concerns about the worries of those closest to you	21% (17)	Psychological
9	talking to other people about the cancer	20% (16)	no domain
9	nausea and/or vomiting	20% (16)	Physical / daily living
9	anxiety	20% (16)	Psychological
9	accepting changes in your appearance	20% (16)	Psychological
9	uncertainty about the future	20% (16)	Psychological
9	opportunity to talk to someone who understands and has been through a similar experience	20% (16)	Health System / Information
15	being informed about things you can do to help yourself get well	19% (15)	Health System / Information

These findings echo the experiences women report to feel at this time in their cancer journey, and the medical characteristics of this sample. The physical responses to illness and treatment appear to have settled in for many respondents, with practical implications on their lives. Energy, sleep, and activities of daily living are reportedly impacted by many, while some have the additional challenge of nausea and/or vomiting. Furthermore, women's fears about the cancer and their future are still often unresolved at this stage, and anxiety about treatment remains. This result reflects that many are still in active treatment, and almost half of the respondents do not know their cancer is in remission.

### **5.3.3. Access to Services - Time Two**

Presumably, improved access to services has the potential to alleviate or minimise high unmet needs. Over half of respondents did not have any high unmet needs for access to services at three months post-diagnosis (58%). Seventeen percent of respondents reported needing access to one service at three months post-

diagnosis. When comparing access to services across sites at Time Two, participants from the *Public / Private Hospital RBN Site* reported the greatest unmet needs, while participants from the *Private Hospital RBN Site* reported the fewest. Table 8 presents the percentage of respondents reporting high unmet needs for access to services at three months post-diagnosis.

**Table 8: Percentage of high unmet needs reported for access to services at three-months (T2) post-diagnosis**

SERVICE	T2
easy parking at the hospital or clinic	33%
transport service to and from the hospital or clinic	10%
monetary allowance for travel, treatment and equipment expenses	10%
drop-in counselling and support service	9%
relaxation classes	9%
brochures about services and benefits for patients with cancer	8%
home gardening service	8%
24-hour telephone support and cancer advisory service	8%
home cleaning service	7%
home nursing service	5%
counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family / partner	5%
library of books and videos about cancer and related issues	5%
comfortable waiting area	4%
respite care	4%
food and drink facilities in or near the clinic waiting room	4%
child-minding at the hospital or clinic	1%

The unmet need most often reported for better access to services at three months post-diagnosis was for ‘easy parking at the hospital or clinic’ (33%). Other unmet service access needs were reported by 10% or less of respondents. These findings suggest most respondents were having their needs for services met, with the exception of easy parking which was by far the most prevalent high unmet need for access to services.

In summary, the respondents at three months post-diagnosis were generally married or partnered and, on average, were slightly younger than cancer registry statistics. The majority of the women were still in active treatment, most



commonly chemotherapy, and almost all had undergone cancer surgery previously. Just over half understood their cancer to be in remission. The most prevalent unmet needs were mixed between the Physical and Daily Living and Psychological domains. These findings indicate that Physical and Daily Living needs are of prominent importance at three months post-diagnosis, reflecting the negative impact of cancer treatments on women's everyday life. Additionally, some psychological concerns remain at this time. The findings suggest women's access to services were relatively good, apart for easy parking to attend treatment or consultations.

## **5.4. Changing Patterns of High Unmet Needs**

The changes between the experiences for respondents at the two survey points provide an image of their journey, and reflect changes in treatments and high unmet needs. Differences between the respondents' medical and demographic characteristics at the survey points give a picture of who responded, and what is happening for these women in their cancer journey. Changes in high unmet needs over time reflect changing needs and/or intensity of need as well as the effectiveness of support and care provided to the individual. The changing patterns of prevalent high unmet needs over time were analysed for specific items and for domains, and are reported in the following sections, along with the sample characteristic changes<sup>23</sup>.

### **5.4.1. Sample – Time One and Time Two**

The medical and demographic characteristics were consistent across the two time points, with the exception of 'cancer treatments received ever' which point to the treatments undertaken by respondents in between the two surveys collection

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<sup>23</sup> Data from all participants were used in the analysis unless otherwise stated (e.g. in section 5.3.2.3 only data from participants who completed both surveys was used).

points. The sample respondents at both survey points were primarily married or living with a partner and aged 41 – 70 years, with respondents at Time One presenting with a slightly younger age profile. The majority of participants from both collection periods had learned of their cancer within the last 6 months, and their most recent hospital treatment for cancer had been within the last month. Approximately half of the respondents from both survey points understood their cancer to be in remission. At one month post-diagnosis, respondents typically had undergone surgery in the last month, while respondents at three months post-diagnosis typically had received chemotherapy in the last month. Respondents at Time Two were more likely to have undergone hormone treatment than at Time One (46% as compared to 31%).

#### **5.4.2. Prevalence of Unmet Needs – Change of Patterns**

In some areas, women's experiences improved between Time One and Time Two, and in others they worsened. The mean number of high unmet needs (out of 59 possible items) for all respondents decreased from one month to three months post-diagnosis from 8.3 to 7.7 items. As the number of high unmet needs changed for respondents, so did the most prevalent items and domains.

##### **5.4.2.1. Unmet Needs with the Greatest Changes of Prevalence**

Changes to individual high unmet need items are likely to reflect both changing needs and the care received from the RBN and others. The change represents either an improved or worsened journey for women.

Changes in high unmet needs items which reflected a worsening experience for respondents from one month to three months post-diagnosis are listed in Table 9. Six unmet need items had >8% increase in prevalence. The items demonstrating increases in high unmet needs were dominated by the Physical and Daily Living domain with 'nausea and/or vomiting' presenting with the greatest increase in prevalence (+16%). These high unmet needs are around how people are feeling

(e.g. tired), sleeping, and working. One item from within the Psychological domain presented as a worsening experience for women as well, namely ‘accepting changes in your appearance’ (+9%). These results are consistent with the sample’s medical characteristics reflecting more women having undertaken chemotherapy and other cancer treatments which often result in these physical challenges.

**Table 9: Items with the greatest increase in high unmet needs from one month (T1) to three months (T2) post-diagnosis (i.e. women’s experiences *worsened* in these areas)**

ITEM	T1	T2	DOMAIN	CHANGE
nausea and/or vomiting	4%	20%	Physical / daily living	16%
not sleeping well	15%	26%	Physical / daily living	11%
feeling unwell a lot of the time	6%	15%	Physical / daily living	9%
lack of energy or tiredness	22%	31%	Physical / daily living	9%
accepting changes in your appearance	11%	20%	Psychological	9%
work around the home	12%	21%	Physical / daily living	9%

Changes in unmet needs items which reflected an improved experience for women from one month to three months post-diagnosis are listed in Table 10. Eight items decreased in prevalence by >8%. Of these unmet needs, six items were from the Psychological domain, and two from the Health System and Information domain. These unmet needs revolved around women’s worries, fears and uncertainty, as well as about being informed. The item demonstrating the greatest improvement for respondents was ‘concerns about the worries of those closest to you’ (-19%). These results suggest women’s concerns have lessened or been resolved, possibly due to the clarification of their health status (e.g. remission and/or successful surgical results), and/or due to the supportive care they received.

**Table 10: Items with the greatest decrease in high unmet needs from one month (T1) to three months (T2) post-diagnosis (i.e. women's experiences *improved* in these areas)**

ITEM	T1	T2	DOMAIN	CHANGE
concerns about the worries of those closest to you	40%	21%	Psychological	-19%
being adequately informed about the benefits and side-effects of treatments before you choose to have them	22%	9%	Health System / Information	-13%
fears about cancer spreading	35%	22%	Psychological	-13%
being informed about your test results as soon as feasible	20%	10%	Health System / Information	-10%
worry that the results of treatment are beyond your control	27%	17%	Psychological	-10%
fears about the cancer returning	32%	22%	Psychological	-10%
changes to your usual routine and lifestyle	26%	16%	Psychological	-10%
uncertainty about the future	29%	20%	Psychological	-9%

A full table listing the prevalence of high unmet needs for all items at time one and time two is included at Appendix 10.

#### **5.4.2.2. Changes in Most Prevalent Items**

The most prevalent high unmet needs compared across time points are presented in this section. Greater than or equal to 20% of respondents reported high unmet needs at one month and three months post-diagnosis on 12 and 14 items respectively. The items reported by over 20% of respondents at either survey collection period are reported in Table 11. Only items from the Psychological, Health System and Information, and Physical and Daily Living domains were reported by over 20% of respondents at either time point. All of these high unmet need items from the Psychological and Health System and Information domains decreased in prevalence at three months post-diagnosis as compared to one month post-diagnosis. Conversely, all of the Physical and Daily Living unmet needs increased in prevalence during the same time. These results mirror the changes to

specific high unmet needs items discussed in the last section in the general areas of improved and worsened experiences for women<sup>24</sup>.

**Table 11: Items reported by >20% of respondents as high unmet needs at one month (T1) and/or three months post-diagnosis (T2)**

DOMAIN	ITEM	T1 n=74	T2 n=83	CHANGE
Psychological	concerns about the worries of those closest to you	40%	21%	-19%
Psychological	fears about cancer spreading	35%	22%	-13%
Psychological	fears about cancer returning	32%	22%	-10%
Psychological	anxiety about having any treatment	30%	26%	-4%
Psychological	uncertainty about future	29%	20%	-9%
Psychological	worry that treatment results are beyond your control	27%	17%	-10%
Psychological	changes to usual routine and lifestyle	26%	16%	-10%
Psychological	concerns about the ability of those close to you to cope with caring for you	20%	13%	-7%
Health System & Information	informed about things you can do to help yourself get well	23%	19%	-4%
Health System & Information	adequately informed about benefits and side-effects of treatments before you choose to have them	22%	9%	-13%
Health System & Information	informed about test results as soon as feasible	20%	10%	-10%
Physical & Daily Living	lack of energy and tiredness	22%	31%	+9%
Physical & Daily Living	not sleeping well	15%	26%	+11%
Physical & Daily Living	not being able to do the things you used to do	19%	24%	+5%
Physical & Daily Living	work around the home	12%	21%	+9%

#### 5.4.2.3. Changes in Most Prevalent Domains

Changes in the mean domain unmet needs illuminate the ‘big picture’ shifts in challenging issues for respondents. Analyses of needs patterns over time were restricted to respondents who submitted surveys at both one month and three

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<sup>24</sup> The only exception being ‘accepting changes to your appearance’ (from the Psychological domain) which was reported by <20% of respondents but rounded up.

months post-diagnosis (n=63). The data was assessed to be normally distributed for the psychological domain, but skewed for the other domains and overall. In this section, the domain changes in unmet needs are presented quantitatively in mean unmet needs by domains, discussed, and displayed visually.

Overall, high unmet needs demonstrated a trend towards a decrease over time which did not reach statistical significance ( $p=.057$ ). The mean number of high unmet needs at one month post-diagnosis was 8.03, and 6.02 at three months post-diagnosis. When analysing differences in mean domain unmet needs, it is important to remember that each domain did not contain the same number of need items, ranging from 3 to 22 items. Thus direct comparison between domains is inappropriate. Mean unmet needs overall and within domains at both survey points are given in Table 12 including the values indicating the level of statistical certainty.

**Table 12: Mean moderate to high unmet needs at one month (T1) and three months (T2) post-diagnosis by domains (n=63)**

Domain (# items)	T1	T2	P value
Psychological (22)	4.37	3.05	.025 <sup>a</sup>
Health System & Information (15)	1.92	0.87	.012 <sup>b</sup>
Physical & Daily Living (7)	0.87	1.29	.163 <sup>b</sup>
Patient Care & Support (8)	0.27	0.14	.240 <sup>b</sup>
Sexuality (3)	0.10	0.19	.000 <sup>c</sup>
OVERALL (59)	8.03	6.02	.057 <sup>b</sup>

a. T-test for paired samples (parametric)

b. Wilcoxon Signed Ranks Test for related samples (non-parametric)

c. Chi squared (non-parametric)

Unmet needs in the Psychological and Health System and Information domains decreased statistically significantly ( $p=.025$  and  $p=.012$  respectively) from one month to three months post-diagnosis. Whereas, during the same time, the

Sexuality domain demonstrated a small but statistically significant ( $p=.000$ ) increase in unmet needs. Physical and Daily Living unmet needs increased, but did not reach statistical significance ( $p=.163$ ).

Identification of these domain changes strengthens the findings for items of greatest change, and changes to most prevalent unmet need items, and also further clarifies the picture of women's experiences. The worsening experiences for women around sexuality issues is an important finding. Moreover, the statistically significant changes to domain unmet needs strengthens the certainty of the picture of women's experiences.

#### **5.4.3. Access to Services – Time One and Time Two**

Respondents' high unmet needs for access to services across time are presented in this section. The majority of respondents did not have any high unmet needs for access to services at one month and three months post-diagnosis (60% and 58% respectively). Nineteen percent of respondents reported needing access to one service at one month and 17% at three months post-diagnosis. Changes in unmet needs for access to services varied across sites. The Private Hospital RBN Site participants were the only group to report decreasing high unmet needs for access to services, while participants from the Community and Public / Private Hospital RBN Sites reported increases in high unmet needs for access to services. Table 13 presents the change of percentage of respondents reporting high unmet needs for access to services between the survey points.

**Table 13: High unmet needs reported for access to services at one (T1) and three-months (T2) post-diagnosis, and the percentage change between the two survey points**

Moderate to high level of need for access to:	T1	T2	Change
easy parking at the hospital or clinic	23%	33%	+10%
transport service to and from the hospital or clinic	4%	10%	+6%
home nursing service	1%	5%	+4%
respite care	0%	4%	+4%
monetary allowance for travel, treatment and equipment expenses	7%	10%	+3%
drop-in counselling and support service	6%	9%	+3%
comfortable waiting area	1%	4%	+3%
home gardening service	6%	8%	+2%
food and drink facilities in or near the clinic waiting room	3%	4%	+1%
child-minding at the hospital or clinic	0%	1%	+1%
brochures about services and benefits for patients with cancer	8%	8%	0%
home cleaning service	7%	7%	0%
counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family / partner	5%	5%	0%
24-hour telephone support and cancer advisory service	9%	8%	-1%
relaxation classes	10%	9%	-1%
library of books and videos about cancer and related issues	7%	5%	-2%

The unmet need most often reported for better access to services at both survey points was for ‘easy parking at the hospital or clinic’. Other unmet service access needs were reported by 10% or less of respondents. Overall, the prevalence of high unmet needs for access to services generally increased slightly, yet little change was seen across time points. Of note, the majority of changes were slight increases nonetheless. The greatest increases in the prevalence of high unmet needs was in ‘easy parking at the hospital or clinic’ (+10%), and ‘transport service to and from the hospital or clinic’ (+6%). The prevalence of all other high unmet needs for access to services increased by 4% or less. These findings suggest that practical considerations such as parking and transport for treatment increase in importance as women are further along in their treatment, perhaps linked to tiredness and fatigue.



In summary, patterns of high unmet needs demonstrated changes from one month to three months post-diagnosis. These findings provide a clear picture of women's changing experiences. More individual items improved for women, than worsened (8 compared to 6). The high unmet needs that increased in prevalence were primarily representing the Physical and Daily Living domain, whereas those items which decreased in prevalence were primarily from the Psychological domain, but also included two from the Health System and Information domain. These findings for specific unmet needs items were reflected in the mean domain results. Statistically significant improvements were found in the Psychological and Health System and Information domains. Although the mean unmet needs in the Physical and Daily Living domain increased, and the overall mean needs decreased, both lacked statistical significance. However, the specific item changes did not reflect the small but statistically significant increases in mean unmet needs within the Sexuality domain.

Women's high unmet needs changed between one month and three months post-diagnosis. It is likely that as cancer treatment responses set in, women experienced greater needs around Physical and Daily Living. It also appears that as circumstances changed for women, care was provided, and time elapsed, many concerns and queries were relieved. It is likely that the generally positive access to services, including an RBN, supported these improvements.

## **5.5. Comparing with Previous Studies**

Comparing results across studies utilising the same assessment tool allows for comparisons of relative healthcare system responsiveness to patient's needs in different populations at different times. Results can often be understood best in relation to other results using the same instrument, which is the case for the SCNS. Although the SCNS has its limitations (most notably, its reliance on self-report), it is the most commonly used tool to assess supportive care needs in Australia. Therefore, notwithstanding its limitations, comparisons of SCNS results across

studies provide a basis for understanding the relative results. This thinking was clearly accepted by other researchers as these results were considered publishable in an international journal (Minstrell, et al., 2008). Thus this reference data is important.

Previous needs assessments (Girgis, et al., 2000; Li & Girgis, 2006; Sanson-Fisher, et al., 2000; Steginga, et al., 2001) utilising the SCNS lend themselves for comparison. These studies vary in their sample demographics, cancer type, stage in the cancer journey, survey administered, and the context in which respondents were utilising and receiving healthcare services. The SCNS findings used for comparison are summarised in the Table 14 below.

**Table 14: Samples utilised for comparisons of Supportive Care Needs Survey results**

REPORTED	SAMPLE	SUB SAMPLES	WHERE	TIME in JOURNEY	YEAR
Sanson-Fisher et al 2000 AND Li & Girgis 2006	General cancer n = 888	n = 825 all except lung n = 63 lung cancer	New South Wales, AUS	Patients attending surgical, medical or radiation oncology departs	1996-1997
Girgis et al 2000	Breast cancer n = 229	n = 100 urban n = 129 rural	New South Wales, AUS	Patients attending surgical, medical or radiation oncology departs	1995-1996
Steinga et al 2001	Prostate cancer n = 206	n/a	Queensland, AUS	Support group participants with over 50% from 1 to 5 years post-diagnosis	2000

The most suitable group for comparison was the Australian breast cancer sample reported by Girgis and colleagues, most specifically the rural breast cancer sub-sample (Girgis, et al., 2000). The rural respondents were primarily between three and five years post diagnosis (69%), with a quarter over five years post-diagnosis (25%) and five percent 2-3 years post diagnosis. Rural respondents were from New South Wales (NSW) Australia and lived > 50km from an urban postcode. This study also included a sample of urban women, with a similar pattern of time since diagnosis (29% >5 years ago, 61% 3-5 years ago, 4% 2-3 years ago, and 6% <2 years ago). Participants were identified through the cancer registry and confirmed

through their General Practitioners. It is unlikely that the rural participants had access to a BN, where possibly half of the urban participants would have had access to such a role. The rural and urban samples had 55% and 51% response rates respectively. Sixty-nine percent of the sample were married (71% of rural respondents and 66% of urban respondents).

Another valuable set of results for comparison came from a study of general cancer patients (Sanson-Fisher, et al., 2000). This sample was recruited from patients attending hospital surgical, medical or radiation oncology departments. A 65% response rate was attained. A secondary analysis was undertaken which separated out respondents by cancer diagnosis, and identified mean domain needs (Li & Girgis, 2006). Of the sample of cancer patients excluding lung, respondents included 47% less than six months, 28% 6 months to two years, and 24% over two years since diagnosis.

Finally, results were also compared with a prostate cancer sample from Queensland Australia (Steginga, et al., 2001). This sample was recruited from seven self-help groups and attained a 62% response rate. Twenty nine percent were within their first year since diagnosis, 51% were between one and five years since diagnosis, and 20% over 5 years since diagnosis. This is an interesting group for comparison as all were receiving a form of supportive care (i.e. support group).

Where appropriate data were available, results were first and foremost compared with the results of previous studies with Australian breast cancer populations which used the SCNS. The three months post-diagnosis results from this study were most suitable for comparison with survey administration timing in previous studies. From these comparisons we learn how the levels of unmet high needs for these

respondents compare to other cancer samples. Thus relatively speaking, the quality of their cancer journey is illuminated<sup>25</sup>.

### **5.5.1. Items of Most Prevalence - Comparisons**

The most prevalent items of high unmet need were compared across relevant samples when findings were publicly available. Table 15 presents the items available for comparison with this study when compared to the rural and urban breast cancer, and general cancer samples (Girgis, et al., 2000; Sanson-Fisher, et al., 2000). The results available for comparison were the ten most prevalent high unmet needs of general cancer patients (Sanson-Fisher, et al., 2000), and the fifteen most prevalent high unmet needs of breast cancer patients (Girgis, et al., 2000). Thus, the most prevalent high unmet needs from other studies were compared with prevalence of those same items within this study.

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<sup>25</sup> However, it should be noted the samples used for comparison were surveyed further along in their cancer journey. It is possible supportive care needs increase again later in the cancer journey. Similarly, McDowell et al (2010) found longer time since diagnosis a consistent predictor of unmet needs. Therefore, it could be the women in this study had not yet reached the time when needs again increase.

**Table 15: Most prevalent high unmet needs from relevant samples as compared to this sample at three months post-diagnosis**

DOMAIN	ITEM	Rural breast (a) n=83	Rural breast (b) n=129	Urban breast (b) n=100	General Cancer (c) n=888
Physical & Daily Living	lack of energy and tiredness	30.9%	28%	28%	33%
Physical & Daily Living	not being able to do the things you used to do	24.4%	-	-	33%
Psychological	fears about cancer spreading	22.0%	55%	41%	40%
Psychological	fears about cancer returning	22.0%	55%	41%	39%
Psychological	concerns about the worries of those closest to you	20.7%	-	-	38%
Psychological	anxiety	19.5%	40%	34%	-
Health System & Information	opportunity to talk to someone who understands and has been through a similar experience	19.5%	33%	34%	-
Psychological	uncertainty about the future	19.5%	-	-	32%
Health System & Information	informed about things you can do to help yourself get well	18.5%	44%	40%	36%
Health System & Information	informed about cancer which is under control or diminishing (i.e. remission)	13.6%	45%	37%	32%
Psychological	feeling down or depressed	13.4%	33%	29%	-
Psychological	concerns about the ability of those close to you to cope with care for you	13.4%	-	-	30%
Health System & Information	given explanations of those tests for which you would like explanations	11.0%	40%	43%	-
Health System & Information	given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	9.8%	30%	30%	-
Health System & Information	informed about your test results as soon as feasible	9.8%	45%	44%	31%
Health System & Information	adequately informed about the benefits and side-effects of treatments before you choose to have them	8.6%	44%	42%	-
Health System & Information	informed about support groups in your area	8.6%	31%	33%	-

(a) three months post diagnosis in this study (Minstrell et al 2008); (b) Girgis et al 2000; (c) Sanson-Fisher et al 2000

The prevalence of high unmet need for this sample was consistently lower than those reported by other relevant samples, with the exception of lack of energy and tiredness. However, the breast cancer samples were provided with a different version of the survey, thus some items of high prevalence were not contained in this nor the general cancer study and vice versa. Additionally, as only the most

prevalent unmet needs were reported in these samples, all results were not available for comparison<sup>26</sup>. Notably, Table 15 does not include some items reported by more than 20% of respondents as high unmet needs at three months post diagnosis in this study. Namely, 'not sleeping well', 'anxiety about having treatment', and 'work around the home' are not included as findings were not available for comparison (26%, 26%, and 21% respectively).

The most suitable sample for comparison was a rural Australian breast cancer sample (Girgis, et al., 2000). In most instances, the high unmet needs reported at three months post-diagnosis in this study were significantly lower than those reported in the previous Australian rural breast cancer sample (Girgis, et al., 2000). Table 16 displays 'lack of energy or tiredness' as the only item - of 13 of the highest unmet needs available for comparison - which did not demonstrate a statistically significant difference. This includes all items available for comparison.

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<sup>26</sup> When results were not available, this was marked with a (-) within the table.

**Table 16: Prevalence of high unmet needs at three months post-diagnosis in this study compared to previous rural breast cancer results (Girgis, et al., 2000)**

DOMAIN	ITEM	Rural breast (a) n=83	Rural breast (b) n=129	P Value
Physical & Daily Living	lack of energy and tiredness	30.9%	28%	0.6501
Psychological	fears about cancer spreading	22.0%	55%	0.0000
Psychological	fears about cancer returning	22.0%	55%	0.0000
Psychological	anxiety	19.5%	40%	0.0018
Health System & Information	opportunity to talk to someone who understands and has been through a similar experience	19.5%	33%	0.0321
Health System & Information	informed about things you can do to help yourself get well	18.5%	44%	0.0001
Health System & Information	informed about cancer which is under control or diminishing (i.e. remission)	13.6%	45%	0.0000
Psychological	feeling down or depressed	13.4%	33%	0.0014
Health System & Information	given explanations of those tests for which you would like explanations	11.0%	40%	0.0000
Health System & Information	given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	9.8%	30%	0.0005
Health System & Information	informed about your test results as soon as feasible	9.8%	45%	0.0000
Health System & Information	adequately informed about the benefits and side-effects of treatments before you choose to have them	8.6%	44%	0.0000
Health System & Information	informed about support groups in your area	8.6%	31%	0.0001

(a) three months post diagnosis in this study (Minstrell et al 2008); (b) Girgis et al 2000

Generally speaking, the high unmet needs of the time two respondents from this study were substantially lower than those reported in previous studies utilising the SCNS or its predecessor. ‘Lack of energy or tiredness’ is the one item which appears to be consistent with previous findings. Tiredness is a symptom that is challenging to expect Health Professionals, including RBNs, to fully resolve. Instead, managing the symptoms and one’s life is considered best practice, with a realistic intention to improve but not completely remove the cancer-related fatigue. Thus, tiredness is physical symptom that cannot fully be ‘fixed’ by RBNs. In contrast, Health System and Information needs could, in most instances, realistically be met by RBNs and others.

### 5.5.2. Mean Unmet Needs - Comparisons

This section presents comparisons of mean high unmet needs overall, and within domains. When compared to previous studies, the mean number of high unmet needs reported was on the lower end, with only melanoma patients reporting lower unmet needs. The mean high unmet needs reported in this study at three months post-diagnosis was qualitatively lower than a previous breast cancer sample, with 7.7 versus 11.8 unmet needs respectively (Li & Girgis, 2006) (available data did not allow statistical testing for differences). Table 17 displays the mean high unmet needs across various samples.

**Table 17: Mean number of high unmet needs reported per patient group – with a maximum of 59 possible needs (Li & Girgis, 2006)**

SAMPLE	T1 (n=74)	T2 (n=83)	Breast (n=276)	Bowel (n=144)	Prostate (n=74)	Melanoma (n=41)	Lung (n=63)	Cancer excl lung (n=825)
MEAN NEEDS	8.26	7.71	11.8	11.4	7.8	6.2	15.6	10.9

The mean number of unmet needs for each domain was compared with the results from one previous study (Li & Girgis, 2006), being the only published findings available for comparison. The mean number of high unmet needs within each domain was generally lower than that reported for general cancer and lung cancer patients attending surgical or oncological departments. The Physical and Daily Living domain at Time Two was the only exception, with this study's respondents reporting similar mean unmet needs to general cancer patients (excluding lung cancer patients). Table 18 displays the results available for comparison.



**Table 18: Mean number of high unmet needs within domains reported by women with breast cancer at one month (T1) and three months (T2) post-diagnosis in this study, compared to general cancer (n=825) and lung cancer (n=63) patients (Li & Girgis, 2006)**

DOMAINS	T1	T2	General Cancer excluding lung	Lung Cancer
Psychological	4.26	3.57	5	7.6
Health System and Information	2.12	1.58	3.3	3.9
Physical and Daily Living	0.91	1.47	1.4	2.8
Patient Care and Support	0.34	0.35	0.8	1
Sexuality	0.12	0.22	0.4	0.4

### **5.5.3. Access to Services - Comparisons**

Comparisons of access to services between time two of this study and previous studies illustrated fewer reported high unmet needs across items for the participants of this study. Results were compared with the relevant Australian samples described earlier. Table 19 presents the prevalence of high unmet needs for access to services for multiple studies.

**Table 19: Results comparisons of high unmet needs for access to services**

	T2	Rural Breast (A)	Urban Breast (A)	General Cancer (B)	Prostate (C)
<b>Moderate to high level of need for access to:</b>					
easy parking at the hospital or clinic	33%	29%	35%	28%	14%
monetary allowance for travel, treatment and equipment expenses	10%	23%	15%	19%	15%
transport service to and from the hospital or clinic	10%	12%	13%	11%	<10%
drop-in counselling and support service	9%	22%	23%	14%	14%
relaxation classes	9%	19%	25%	15%	11%
24-hour telephone support and cancer advisory service	8%	24%	29%	17%	13%
brochures about services and benefits for patients with cancer	8%	20%	24%	17%	20%
home gardening service	8%	n/a	n/a	11%	<10%
home cleaning service	7%	n/a	n/a	12%	<10%
library of books and videos about cancer and related issues	5%	26%	21%	18%	19%
home nursing service	5%	9%	6%	9%	<10%
counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family / partner	5%	n/a	n/a	12%	19%
food and drink facilities in or near the clinic waiting room	4%	9%	8%	9%	<10%
respite care	4%	7%	8%	8%	<10%
comfortable waiting area	4%	n/a	n/a	11%	<10%
child-minding at the hospital or clinic	1%	4%	2%	3%	<10%

Key: T2 = three months post-diagnosis in this study (Minstrell, et al., 2008); A = (Girgis, et al., 2000); B= (Sanson-Fisher, et al., 2000); C= (Steginga, et al., 2001)

‘Easy parking at the hospital or clinic’ was consistently the highest unmet need for access reported within each sample, with the exception of men with prostate cancer. Unmet needs for better access to services were lower in this study, with only one item (i.e. easy parking) reported by equal or >20% compared to six items in the previous rural and urban breast cancer samples (Girgis, et al., 2000). Consistent with this study, Sanson-Fisher et al (Sanson-Fisher, et al., 2000) reported only one unmet access need by more than 20% of general cancer patient respondents. However, more than 10% of general cancer respondents reported unmet access needs on eleven other items for access to services, whereas this study did not have any other access to service items exceeding 10% of respondents reporting high unmet needs.

Findings on unmet needs for better access to services from this study were most consistent to those of prostate cancer patients attending peer-help support groups in Queensland Australia (Steginga, et al., 2001). Though, more respondents with prostate cancer reported unmet needs for access to information services, namely brochures, and books or videos. Yet fewer respondents with prostate cancer reported high unmet needs for 'easy parking at the hospital or clinic' than did women who participated in this study. It should be noted that gender differences could account for some of the differences in findings. For example, it is unlikely that the men in the prostate cancer sample were responsible for childcare or domestic duties.

In summary, the ability to compare the high unmet needs findings of this sample with other samples provides greater context for understanding these results. In comparison to other Australian cancer groups and breast cancer samples specifically, the women in this study reported to have their supportive care needs met relatively well. 'Lack of energy or tiredness' was consistently reported across samples as an enduring unmet need. The mean high unmet needs overall and within domains for this study were generally lower than the other sample findings available for comparison. The exceptions were melanoma patients reporting fewer overall unmet needs, prostate cancer patients reporting similar unmet needs to this study, and the Physical and Daily Living unmet domain needs being consistent with general cancer patients (excluding lung cancer). Unmet needs for access to services were consistently lower with this sample as compared to others, with the exception of prostate cancer patients attending support groups. However, 'easy parking at the hospital or clinic' was a consistent and persistent high unmet need across samples.

## **5.6. Chapter Conclusions**

This chapter illustrated RBN clients were having their supportive care needs met relatively well. Also, there were important changes in RBN client's high unmet

needs over the first three months of their illness. Respondents generally fit demographic profiles in age and marriage/partner status, though their average age was younger than cancer registry data. Respondents' medical experiences were generally consistent with standard procedure.

At one month post-diagnosis participants had almost all recently undergone surgery while one in three was receiving chemotherapy and one in five hormone treatment. Their most prevalent high unmet needs were related to the Psychological domain, namely concerns, fears, anxiety, and uncertainty, yet also included some items within the Health System and Information domains. Participants' access to services was generally favourable. It seems likely that the recent diagnosis with a life-threatening illness left women considering many personal issues, and battling their own fears and concerns.

At three months post-diagnosis participants, respondents were generally undergoing active treatment, most commonly chemotherapy, hormone therapy and/or radiotherapy. The most prevalent unmet needs were primarily from the Physical and Daily Living domain, while the Psychological domain items also were prevalent. Again, participant's access to services was generally favourable, yet easy parking for cancer care was reported as a high unmet need by one in three respondents. These findings suggest the physical impacts of cancer treatment were negatively impacting women's daily living experiences.

The changing patterns of high unmet need between one month and three months post-diagnosis provide a clear and resounding picture of women's experiences. While overall high unmet needs decreased over time, there were important differences in the patterns of change. The high unmet need items of greatest change coupled with the changes in the most prevalent unmet needs echo the worsening physical and daily living experiences for women, and improved psychological position along with fewer high unmet needs for Health System and Information items. The statistically significant differences in domain changes across time reiterate these findings and further extend their validity. Furthermore, a

statistically significant worsening in women's experiences around Sexuality issues was identified. Access to services was relatively consistent, yet women's high unmet needs for easy parking increased.

Comparisons between the unmet supportive care needs profile of this sample with other samples demonstrates these women's needs were being met relatively well. While the relatively low prevalence of high unmet needs demonstrated within this study could be due to many reasons, it seems likely that one significant contributor would have been the presence and involvement of the RBN in women's care. These results suggest not all high unmet needs can be alleviated for all women, yet significant improvements in meeting needs were seen in comparison to other samples. Importantly, the women in this study reported fewer high unmet needs around Health System and Information as well as Psychological domain issues. These results suggest the improved unmet needs profile is due, at least in part, to the involvement of the RBN and her care.

This chapter described the outcomes for women who consult RBNs, specifically the prevalence and patterns of high unmet supportive care needs, and the patient characteristics which contribute to needs and unmet needs. Women's needs are expected to drive RBN actions. Thus the results presented in the upcoming chapters are better understood with the findings of this chapter in mind. These findings are useful in understanding what interventions RBNs undertake in their care with women, including their objective breast nursing practices (Chapter Six), and their subjective breast nursing practices and what influences nursing practices (Chapters Seven and Eight). The next chapter will expand on these findings by describing what happens for women within RBN consultations, demonstrating how RBNs interpret women's needs and the interventions they undertake to alleviate, manage, and pre-empt supportive care needs.

# Chapter Six: Quantitative Descriptions of Rural Breast Nursing Practices

It is useful to know how RBNs' contribute to clients' experiences and outcomes as a part of a wider healthcare system. Specifically, it is useful to understand how RBNs distribute their time across nursing duties, and breast nursing practices in consultations with clients. It is then possible to highlight any discrepancies between urban and rural breast nursing care. Therefore, this chapter addresses the sub-question: *What are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?* The purpose of this chapter is to objectively describe rural breast nursing practices, across varying sites and summarised together<sup>27</sup>. RBN practices are then compared with the NBCC SBN Demonstration Project in order to identify similarities and differences between rural and primarily urban practice.

This chapter quantitatively describes rural breast nursing practices in terms of their overall practices, and the consultations provided to clients. RBN interventions are comprehensively described in terms of their dose, delivery and content. Comparisons are made to urban breast nursing whenever possible. Results are drawn from the analysis of data within RBN Day Logs, Study Patient Lists, and Consultation Logs, as previously described in Chapter Four: Methods<sup>28</sup>.

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<sup>27</sup> The three RBN sites were summarised into a *Summarised RBN* to enable comparisons with urban breast nursing practices.

<sup>28</sup> Also described in the Methods Chapter are the three RBN sites explored within different organisational and healthcare settings across the three regions of Tasmania, Australia. In summary, the sites included the Community RBN, Public/Private Hospital RBN (given access and freedom to work within the linked private hospital while formally placed within the public system), and Private Hospital RBN. Additionally, the

This chapter links with the previous results chapter by describing RBNs' contribution - as one part of a cancer care system - to bring about the supportive care outcomes described in the previous results chapter (Chapter Five).

Results in this chapter are reported in two sections. The first section provides an overarching description of breast nursing practices through distribution of RBN time across duties, hours worked per site, and an estimate of hours worked per client. Non-uniformity of RBN services was anticipated due to the individuality of clients and their needs, diversity of RBNs and their employment arrangements, and the real world conditions under which the study was undertaken.

The second section describes RBNs' interventions with clients in terms of their dose, delivery, and content. Comparisons are made across RBN sites, and the data are combined to describe a *Summarised RBN Site*. RBNs participating in this naturalistic study determined the interventions delivered within the parameters of employing organisations. Thus, consistency of RBN interventions was not expected across sites.

## 6.1. Description of Overall Practice

Similarities and differences between urban and rural breast nursing practices were identified by comparing the *Summarised RBN* with the NBCC SBN Demonstration Project. Figure 8 demonstrates that the proportion of time spent on various duties were markedly similar. Specifically, time use patterns were generally comparable in patient related and non-patient related duties<sup>29</sup>. Two areas of exception were

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Introduction Chapter details the primarily metropolitan or cancer-clinic based NBCC SBN Demonstration Project which implemented the '5 in 12' clinical pathway (SBN Project Team, 2000).

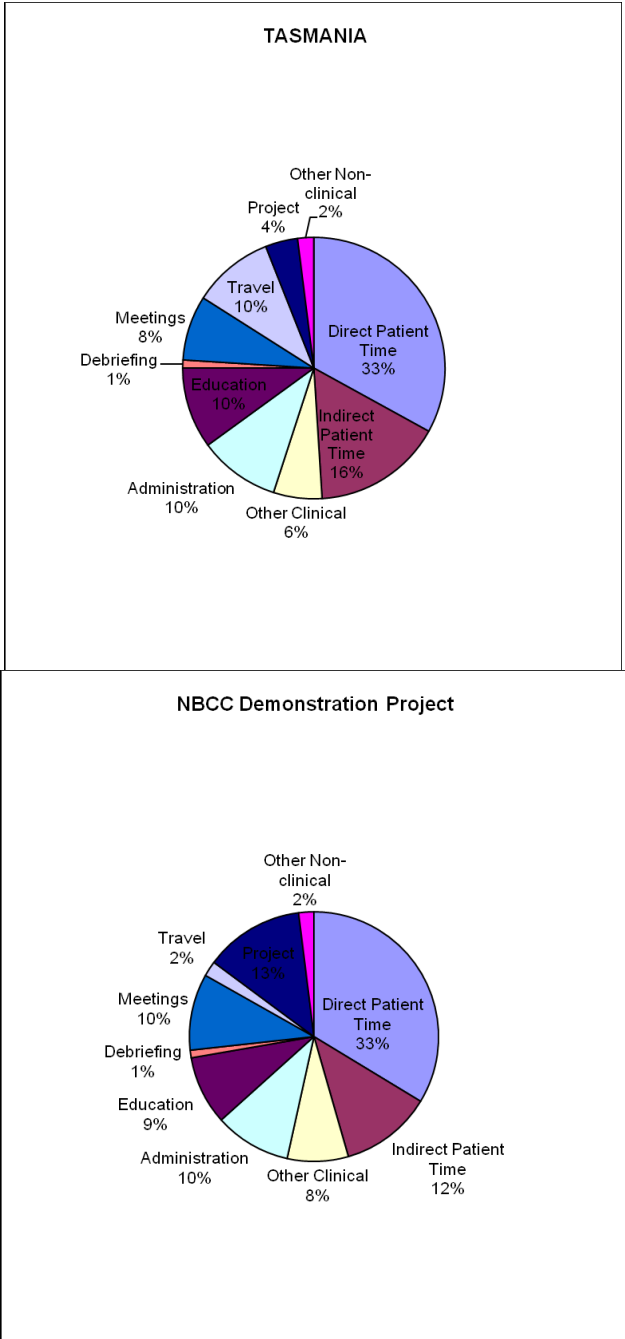
<sup>29</sup> As described in the Methods Chapter, patient related duties included direct and indirect patient time, and other clinical duties. Non-patient related time included administration, education, debriefing, meetings, travel, research/project duties, and other non-clinical duties.

noted, travel (10% and 2% respectively) and project/research duties (4% and 13% respectively).

The broad distribution across breast nursing duties closely resembles one another. An important similarity between the findings of *Summarised RBN* and the NBCC SBN Demonstration Project is the proportion of patient time. Specifically, both devoted one third of their time to direct patient time. Yet, RBNs and SBNs also spent a significant proportion of time on non-patient related duties (45% and 46% respectively). This suggests that despite the rural or urban setting, non-patient related duties will account for nearly half of all BN time.



**Figure 8: Proportion of time spent on various duties for the *Summarised Rural Breast Nurse* and the NBCC SBN Demonstration Project**



The greater proportion of time spent on travel for the *Summarised RBN Site* is not unexpected. As Tasmanian sites were in rural contexts, one would anticipate increased travel time. Although travel time is likely to vary depending on the

setting and physical area covered, it is logical that rural sites would allocate greater time to travel compared to urban counterparts.

The research/project time of nurses' within the NBCC Demonstration Project was over three times as great as that for the RBNs in this study. This suggests that at research/project conclusion, SBNs in the NBCC Project were able to devote more time to direct patient care than RBNs were.

Although rural sites devote more time to travel, it is clear there are striking similarities between how urban and rural breast nurses spend their time. However, not all RBNs go about their breast nursing in the same way. The following section explores the differences between RBN sites.

#### **6.1.1. Diversity across Rural Sites**

Comparing breast nursing practices across rural sites demonstrates the distinct differences between them. Each RBN was at a different site and employment parameters also varied, in hours committed to the role, availability to clients, and the accessibility of clients across healthcare sites.

This section explores the diversity in overarching RBN practice characteristics in terms of RBN hours worked, estimated hours per client, proportion of time spent on non-patient related duties, and the proportion of telephone and face-to-face support. The diversity in broad scale practice characteristics across RBN sites, the *Summarised RBN* and the NBCC SBN Demonstration Project is presented in Table 20.

**Table 20: Broad scale characteristics of RBN Sites, *Summarised RBN*, and NBCC SBN Demonstration Project**

Broad scale characteristic	NBCC SBN Demonstration Project (n = 7)	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public / Private RBN Site (n=1)	Private Hospital RBN Site (n=2)
Mean practice hours worked per week		16.9 (SD 12.3)	30.6 (SD 6.7)	14.0 (SD 7.9)	6.2 (SD 5.9)
Study patients during data collection year	237 (6 months)	239	123 (51%)	64 (27%)	52 (22%)
Practice hours per consulting breast cancer patient		11.0	12.9	11.3	6.2
Estimated breast cancer diagnosis during data collection year*		222	133	52	37
Practice hours per estimated breast cancer diagnosis per year		11.9	12.0	14.0	8.7
Percent of time in patient related duties (i.e. clinical activities)	54%	55%	52%	70%	38%
Percent of time in face to face support	20%	23%	21%	28%	15%
Percent of time in telephone support	4%	7%	6%	9%	10%
Percent of time in non-patient related duties	46%	45%	48%	30%	62%
Percent of time in travel	2%	10%	13%	5%	7%
Percent of time on project / research related duties	13%	4%	4%	5%	5%
Percent of support time delivered face-to-face	83%	71%	78%	76%	60%
Percent of support time delivered by telephone	17%	29%	23%	24%	40%

\*patients are known to travel between regions for treatment

### 6.1.1.1. Practice Hours and Caseloads

RBN hours varied greatly across sites and weeks. RBN hours per week ranged from 6 to >30hrs per week, with the *Private Hospital RBN Site* undertaking the fewest

hours, and the *Community RBN Site* engaging in the most. All RBN sites employed nurses for less than one full time equivalent (38 hours per week), despite the fact that two of the sites included more than one RBN (*Private Hospital* and *Community*). The hours worked within each site also varied across weeks. The weekly variation was especially prominent in the 'add on' role of the *Private Hospital RBN Site*. The dedicated positions of the *Community RBN Site* demonstrated a much smaller relative variation in hours.

RBN sites had different size caseloads, yet caseloads were generally consistent with the distribution of registered breast cancer diagnosis within the state (Dalton et al., 2007; Newman, et al., 2006)<sup>30</sup>. Therefore, different caseloads reflect one obvious reason why RBN hours differed across sites. Moreover, the smaller caseloads found for RBN sites when compared to the NBCC SBN Demonstration Project was also consistent with the NBCC Project's rural site reporting the smallest caseload of all NBCC sites (SBN Project Team, 2000).

#### **6.1.1.2. Hours Required to Support Women**

Analysing nursing hours per client provides valuable information for health service planners to utilise in estimating the likely BN employment hours necessary to provide appropriate support. RBN hours per client were calculated using the estimated hours worked per year and dividing this by the number of study patients<sup>31</sup>.

Estimated nursing hours per client varied considerably across RBN sites. The estimated hours per client ranged from 6.2hrs for the *Private Hospital RBN Site* to 12.9hrs for the *Community RBN Site*, while the *Public/Private Hospital RBN Site* was

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<sup>30</sup> The greatest divergence between the registry diagnosis and client proportions was in the one region where not all women had access to an RBN, specifically in the *Private Hospital RBN Site* where public patients were excluded from RBN care.

<sup>31</sup> As per the RBN held study patient list.

on the higher end with 11.3hrs per client. The average hours worked per client for the *Summarised RBN* was 11hrs per client. However, it should be noted that women with early breast cancer were not the only patients seen by RBNs, as was consistent with the NBCC Project<sup>32</sup>.

Additionally, it is estimated that approximately 11 – 12 RBN hours was undertaken for each breast cancer diagnosis in the region. As patient related duties accounted for approximately half of RBN time, the 11 – 12 hours per client estimation is generally consistent with the NBCC Project which identified approximately 5 hours of patient related duties per patient over the intervention (SBN Project Team, 2000).

### **6.1.1.3. Balancing Patient Related and Non-Patient Related Duties**

This section explores diversity in non-patient related time across rural sites. The significant proportion of BN time spent in non-patient related duties for rural and urban BNs was highlighted earlier. Across rural sites, significant variation in the proportion of non-patient related time was seen. Looking at the other side of the coin, the proportion of time spent on patient-related duties obviously also varied across rural sites. Most notably, the *Public/Private RBN Site* spent 70% of their time on patient related duties while the *Private Hospital Site* spent < 40%<sup>33</sup>.

Possible explanations for the variation in patient-related time include the physical arrangement of health services, the extent to which RBN services were established within the local health systems, and the employment parameters. The

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<sup>32</sup> RBNs consulted beyond the early breast cancer scope, often accepting other clients with recurring disease or outside of the early breast cancer time period. This was confirmed through interviews with RBNs. The NBCC SBN Demonstration Project also identified nurses seeing other patients, whether with other cancer types, or outside the early breast cancer experience (SBN Project Team, 2000).

<sup>33</sup> Given the limited RBN hours within the *Private Hospital RBN Site*, its time proportions could have been skewed due to one half-day meeting or professional development session during data collection (e.g. Breast Nurse Network).

*Public/Private Hospital RBN Site* may have spent a larger proportion of time on patient related activities as their consultations were all in a relatively small area (i.e. walking distance), access was easily attained across public and private hospitals, and the number of health service providers which she corresponded with were minimal (i.e. one primary surgeon). Moreover, this service had been established in the healthcare system for over 15 years, whereas the other RBN services were relatively new and would have spent some time establishing the role.

Significantly, the NBCC SBN Demonstration Project also found “marked differences between centres in the proportion of time dedicated to clinical activities” (SBN Project Team, 2000, p30) or patient-related duties, ranging from 84% to 34% of the nurses’ time. Interestingly, the one rural site within the NBCC Project spent the smallest proportion of time on patient-related duties. It is possible RBNs need to put more time into non-patient related duties, as rural cancer care pathways are more fragmented (McConigley, et al., 2010).

#### **6.1.1.4. Broadening the Reach through Telephone Support**

Providing support directly to women with breast cancer is the BNs’ primary patient-related task. In this study, RBN support was delivered either face-to-face or via the telephone<sup>34</sup>. Importantly, telephone support constituted a significant proportion of support time for RBNs, ranging from 23% to 40% of total support hours, as compared to 17% of the NBCC SBN Demonstration Project. Given the primarily rural clientele, the use of telephone support is not surprising, since face-to-face contact is not always an option or deemed an efficient use of resources.

Interestingly, a consistent relationship was not found for all sites between telephone support time and travel time, and instead two patterns emerged. It

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<sup>34</sup> As detailed in the Methods Chapter, the amount of time involved in telephone and face-to-face support was recorded in nurses’ Day Logs, while Consultation Logs provided more detail about what occurred during each contact and how it was undertaken (further detailed in the *Content* section of this chapter).

appears the *Community RBN Site* travelled more to provide face-to-face support (13% travel, 6% telephone support) whereas the *Private Hospital RBN* and *Public/Private Hospital RBN Sites* spent less time travelling and proportionately more time providing telephone support (7% and 5% travel, 10% and 9% telephone support respectively). When compared to RBN Sites, NBCC Project SBNs spent proportionally less time in travel and in telephone support (2% and 4%). It is likely those SBNs had more opportunities to provide face-to-face support as women booked SBN consultations coinciding with other healthcare visits to the same site.

In summary, this section demonstrated that rural and urban BN sites were similar in their overall use of time, with travel being the primary deviation. Regardless of location, a significant proportion of BN time was spent on non-patient related tasks, yet diversity existed across rural sites. Also, the diversity of RBN sites employment parameters was distinct. Specifically, a range of nursing hours per client and caseloads were found. Yet, it appears 11-12 BN hours per client is necessary. Overall, telephone support was utilised more in rural than urban practices. Furthermore, telephone support was used in hospital-based sites to broaden the reach of RBNs, whereas the community-based site appeared to devote more time to travel in order to meet with women face-to-face.

## **6.2. Description of Consultations**

This section examines the consultations delivered to clients; namely the dose, delivery, and content. The dose refers to the timing, quantity, and duration of consultations. The delivery describes the delivery mode (telephone / face-to-face) and initiation source (nurse / client). The content specifies (RBN perceived) consultation emphasis and interventions provided (i.e. written resources or referrals). Consultations Logs completed by RBNs for all consultations with eligible patients (n=904) provided significant detail about RBN interventions. Additionally, RBN-held Study Patient Lists provided data about the number of consultations undertaken with each woman.

### **6.2.1. Dose – Practice Location affects Accessibility**

This section describes the dose of RBN interventions by the:

- treatment phase in the cancer journey when consultations occurred (i.e. timing),
- total number of consultations per client (i.e. quantity), and
- mean consultation durations (length).

Study Patient Lists primarily provided the data from which these results were derived, while Consultation Logs provided the consultation duration data.

#### **6.2.1.1. Timing: When in the Journey**

Consultation timing impacts RBNs' ability to treat, manage, and prevent problems for women. Timing is important as it affects what needs can be addressed, and which issues can be pre-empted to minimise negative impact. The treatment phases from the NBCC's '5 in 12' clinical pathway were utilised in this study to define consultation timing (SBN Project Team, 2000). The results presented in Table 21 demonstrate the RBN study sites' emphasis on post-operative care.



**Table 21: Consultations across treatment phases for Rural Breast Nurse Sites and NBCC SBN Demonstration Project**

Consultation Characteristic	NBCC SBN Demo Project (n = 7)	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Consultations within '5 in 12 model' (%)		57% (593)	59% (236)	51% (215)	64% (142)
Consultations considered 'other' or additional		43% (446)	41% (161)	49% (204)	36% (81)
Mean consultations per patient (#)		4.4	3.2	6.6	4.4
Mean consultations within '5 in 12' per patient		2.5	1.9	3.4	2.8
Mean 'other consultations' per patient		1.9	1.3	3.2	1.6
Patients receiving diagnosis phase consultation (%)	61%	17%	10%	39%	6%
Patients receiving pre-operative consultation	>93%	43%	25%	58%	69%
Patients receiving post-operative consultation	>93%	70%	59%	84%	80%
Patients receiving 1-6 wks post-operative consultation	>93%	72%	68%	84%	67%
Patients receiving 6-10wks post-operative consultation	>93%	47%	30%	70%	57%

The results show that pre-operative contact was limited, and post-operative emphasis was in the first 6 weeks for the *Summarised RBN*. The most frequent phases for consultations were post-operative and 1 – 6 weeks post-operative. The diagnosis consultation was the least frequent with only 17% of patients receiving this consultation. Under half of patients received pre-operative and 6-10 weeks post-operative consultations. In comparison, the NBCC SBN Demonstration Project reported >90% of patients received consultations during most treatment phases, with the only exception being 61% during the diagnosis phase (SBN Project Team, 2000)<sup>35</sup>. Interestingly, the NBCC Project identified challenges in attaining early referrals despite extensive treatment team support (SBN Project Team, 2000). In contrast to this study's results portraying an emphasis on the post-operative time

<sup>35</sup> These were limited to nurse-initiated consultations, thus the total percentage of clients receiving consultations during these treatment phases may have been even higher.

period, the Victorian BN workforce study identified almost 60% of contact time occurred pre-operatively (Victorian Centre for Nursing Practice Research, 2001).

The greatest proportion of *Public/Private RBN Site* clients received consultations during almost all treatment phases, whereas the *Community RBN Site* was the opposite. Notably, the *Private Hospital RBN Site* reported its highest percentage of clients consulted during pre-operative and post-operative treatment phases, peaking earlier than other RBN sites.

It may be the physical location of RBN services in relation to other cancer services affects the likelihood of consultations at various treatment phases. Indeed, a more centralised RBN office might enable consultations by increasing access and availability of clients and RBNs to one another. For instance, the *Community RBN Site* with the most decentralised office had the smallest proportion of clients receiving pre-operative consultations. Additionally, this site had markedly fewer post-operative consultations than the hospital-based sites.

Interestingly, a significant proportion of RBN consultations were outside of, or additional to the designated treatment phases (i.e. denoted 'other'). The *Summarised RBN* reported 43% of all consultation as 'other', while RBN sites ranged from 49% (*Public/Private Hospital*) to 36% (*Private Hospital*). This is discussed further in the next section.

#### **6.2.1.2. Quantity: Total Consultations per Client**

Another component of RBN intervention dose is the total number of consultations per client. It is generally assumed that more consultations reflect a greater strength of supportive care intervention. Table 21 demonstrates the mean number of consultations per client during treatment phases was lower for *Summarised RBN*

than the NBCC SBN Demonstration Project<sup>36</sup>. However, it appears rural and urban clients received a similar number of consultations overall, as RBNs provided a high proportion of 'other' consultations.

Although rural consultation timing diverged from the '5 in 12' clinical pathway of the NBCC Project, the total number of consultations received by clients were strikingly similar. The similarity between the mean number of consultations provided by the *Summarised RBN* (4.4), and that recommended in the '5-in-12' clinical pathway (5), suggest that 4 - 5 consultations might be an appropriate number to address women's needs. However, the timing of the '5 in 12' consultations may not be suited to all contexts, in particular rural contexts.

The quantity of RBN consultations per client varied significantly across sites. The *Public/Private Hospital Site* had the highest mean consultations per patient, more than double that provided by the *Community RBN Site*. Meanwhile, the *Private Hospital RBN Site* provided approximately one more consultation per client than did the *Community RBN Site*.

Again, the physical location and arrangement of services may have been an important driver in these results. As hospital-based RBNs were located at healthcare sites where surgical procedures were undertaken, this afforded them greater access to women during this stage of their journey. Furthermore, the *Public/Private Hospital RBN Site* was also on the same site as oncological services, thus greatly increasing contact opportunities. On the other hand, the *Community RBN* had to travel to treatment sites or clients' homes to provide face-to-face consultations. Thus, it makes sense the *Community RBN Site* had fewer mean consultations per client.

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<sup>36</sup> Given the '5 in 12' clinical pathway and no details provided about additional client-initiated consultations, it is presumed that the NBCC SBN Demonstration Project averaged approximately 5 consultations per client.

### 6.2.1.3. Duration: Relationship between Length and Strength

Consultation length is also an indicator of RBN intervention dose. Consultation duration can be driven by a number of variables within clients, RBNs, and the wider context<sup>37</sup>. Table 22 summarises the mean consultation durations of RBN sites, including a breakdown for different treatment phases, initiation sources, and delivery modes<sup>38</sup>.

**Table 22: Mean consultation duration across Rural Breast Nurse sites**

KEY: M (+-SD) n

Mean Consultation Minutes (of 904 consult logs)	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Consultation time (minutes)	<b>34</b> (± 26) 853	<b>46</b> (± 28) 319	<b>28</b> (±20) 401	<b>27</b> (±25) 184
Diagnosis phase consultation minutes	<b>49</b> (±30) 37	<b>61</b> (±30) 11	<b>45</b> (±29) 23	<b>33</b> (±25) 3
Pre-operative phase consultation time	<b>41</b> (±25) 98	<b>50</b> (±30) 26	<b>41</b> (±24) 46	<b>33</b> (±16) 26
Post surgery phase consultation time	<b>35</b> (±25) 181	<b>40</b> (±20) 51	<b>34</b> (±20) 92	<b>33</b> (±42) 38
1-6 wks post-operative phase consultation time	<b>38</b> (±29) 202	<b>53</b> (±31) 98	<b>22</b> (±15) 65	<b>25</b> (±20) 39
6-10 wks post-operative phase consultation time	<b>38</b> (±28) 74	<b>49</b> (±30) 34	<b>22</b> (±20) 11	<b>31</b> (±23) 29
Other' phase consultation time	<b>27</b> (±21) 252	<b>41</b> (±26) 74	<b>22</b> (±15) 142	<b>20</b> (±17) 36
Face-to-face consultations	<b>44</b> (±27) 511	<b>59</b> (±27) 185	<b>34</b> (±20) 241	<b>38</b> (±31) 85
Telephone consultations	<b>18</b> (±11) 280	<b>24</b> (±11) 114	<b>12</b> (±6) 102	<b>15</b> (±8) 64
Nurse-initiated consultations	<b>29</b> (±22) 360	<b>38</b> (±25) 113	<b>25</b> (±19) 149	<b>25</b> (±19) 98
Client-initiated consultations	<b>30</b> (±20) 170	<b>41</b> (±25) 48	<b>26</b> (±17) 110	<b>28</b> (±21) 12

While the mean consultation duration for all RBN consultations was 34 minutes, a general trend towards decreased consultation length through the cancer journey is apparent. There was significant variation in consultation durations across RBN sites.

<sup>37</sup> For example, some variables impacting consultation lengths may be clients' willingness to raise and discuss issues, the number and complexity of supportive care issues identified, RBN's skills, propensity and willingness to address challenging issues, and available time and space for RBNs and clients to meet.

<sup>38</sup> RBNs recorded consultation durations within Consultation Logs. Of 904 Consultation Logs, 853 contained relevant data.

Specifically, the *Community RBN Site* had markedly longer consultations than the other RBN sites across all treatment phases, ranging from 40 – 61 minutes.

Initiation source made little difference to consultation duration in this study. Table 22 also reveals that face-to-face consultations were longer than telephone consultations, regardless of initiation source. This finding was consistent across RBN sites. Similarly, the NBCC SBN Demonstration Project also reported longer face-to-face consultations regardless of initiation source (SBN Project Team, 2000)<sup>39</sup>. Interestingly, these results differed from the NBCC SBN Demonstration Project which reported markedly longer consultations when nurse-initiated (SBN Project Team, 2000).

In summary, RBN intervention dose is related to consultations timing, quantity, and duration. The results reveal RBNs' different contact patterns across treatment phases, yet all RBNs reported fewer proportions of clients being consulted than the NBCC Demonstration Project. Also, a strikingly significant proportion of RBN consultations were reported outside or additional to designated treatment phases. The diagnosis consultation was the least frequent for all RBN sites. Generally speaking, the *Public/Private Hospital RBN Site* reported the highest proportion of clients receiving consultations across all treatment phases, while the *Community RBN Site* reported the least. The consultation timing pattern appeared to reflect RBNs' proximity to other cancer services.

While the mean number of consultations per client varied significantly across RBN sites, this also appeared to mirror the RBN's proximity to other cancer services. For instance, the *Public/Private Hospital RBN Site* reported the greatest number of consultations per client, and the *Community RBN Site* reported the fewest. While

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<sup>39</sup> The NBCC SBN Demonstration Project reported nurse-initiated face-to-face consultations averaging one hour and telephone consults 20 – 30 minutes, while patient initiated face-to-face consultations averaged 30 minutes, and telephone consultations 12 – 17 minutes (SBN Project Team, 2000, p31).

RBN clients received consultations at different time points than the NBCC Project, the total number of consultations per client was remarkably similar due to the high number of 'other' consultations provided by RBNs. This supports the idea that 4-5 consultations may be appropriate.

Consultation durations generally decreased through the cancer journey. Face-to-face consultations were consistently longer than those over the telephone for all RBN sites. The *Community RBN Site* reported meaningfully longer consultations across all treatment phases. From these dose results, a picture emerged of the hospital-based RBNs undertaking more consultations of shorter length and the *Community RBNs* undertaking fewer consultations of longer duration.

### **6.2.2. Delivery – Making and Maintaining Contact**

This section describes how RBNs and clients made and maintained contact with one another. Specifically, it presents RBN consultations' delivery mode (face-to-face / telephone), and initiation source (nurse / client). The proportion of face-to-face delivered consultations was calculated for all RBN sites, and broken down across treatment phases<sup>40</sup>. These are presented in Table 23 while Table 24 summarises who initiated RBN consultations. Results provided insights to who initiated consultations despite the fact initiation data was only available for approximately 60% of RBN consultations<sup>41</sup>.

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<sup>40</sup> RBNs indicated the delivery mode and initiation source on Consultation Logs.

<sup>41</sup> Of 904 total Consultation Logs, 41% or 374 of initiation source data points were left blank. This was the largest single point of missing data for Consultation Logs. However, Consultation Logs and Study Patient Lists provided data to compare the initiation source of 'other' consultations. The two data sources results for initiation source were compared. The aim of comparing their results was to identify any existing patterns of item non-response for consultation initiation source. Although there appeared to be general consistency in output results, an across practice non-response pattern was not clear enough to choose to impute missing data, thus the choice was made to exclude missing data.

### 6.2.2.1. Face-to-face or Telephone

Previous studies have raised concerns about the quality of BN care when the proportion of telephone contact outweighs face-to-face contact, and patients' feedback suggests limited face-to-face contact leads to reduced care continuity (SBN Project Team, 2000). Therefore, monitoring RBN consultation delivery modes is important. In this study RBN consultations were typically held face-to-face, yet not as frequently as the NBCC SBN Demonstration Project. Face-to-face consultations were more common than telephone consultations for all RBN sites, yet differences were present across sites. Specifically, the *Public/Private Hospital RBN Site* had the greatest use of face-to-face consultations, while the *Private Hospital RBN Site* had the least.

**Table 23: Consultation delivery mode characteristics across Rural Breast Nurse Sites**

KEY: % (n)

Consultation Characteristic*	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Consultations delivered face-to-face (%)	65% (511)	62% (185)	70% (241)	57% (85)
Consultations delivered by telephone	35% (280)	38% (114)	30% (102)	43% (64)
Diagnosis phase consultations held face-to-face (%)	66%	80%	58%	42%
Pre-operative consultations held face-to-face	78%	54%	87%	13%
Post-operative consultations held face to face	88%	74%	96%	4%
1-6 wks post-operative consultations held face-to-face	50%	63%	41%	59%
6-10 wks post-operative consultations held face-to -face	51%	64%	46%	55%
other' consultations held face-to-face	62%	61%	69%	31%

\*excludes missing data points 12.5% of total (113 missing of 904 total)

It seems likely the physical availability of clients and RBNs to one another increased the proportion of face-to-face consultations. For example, the *Public/Private Hospital RBN* and her clients were most likely to facilitate face-to-face consultations than other sites as this site was in close proximity to the region's surgical and

chemotherapy cancer services. In contrast, other RBNs were not as central to all cancer services, and thus used telephone consultations more often.

However, the *Community RBN Site* demonstrated the most consistent use of face-to-face consultations across all treatment phases, ranging from 54 to 80%.

Combined with the earlier data on travel time, consultation number and duration, this suggests the *Community RBN Site* used a different strategy to consult with clients (i.e. travelling to deliver face-to-face consultations). The influences on consultation delivery mode are explored further in the semi-structured interviews results in the next Chapters (Seven and Eight).

Post-operative consultations were most likely of all treatment phases to be face-to-face for the *Summarised RBN*. However, the general trend was for more face-to-face consultations during earlier rather than later treatment phases. The NBCC SBN Demonstration Project also reported a similar pattern of decreased face-to-face consultations over the cancer journey (SBN Project Team, 2000, p144).

Decreasing face-to-face consultations could be explained a number of ways. RBNs may have prioritised initially meeting with a client in person (when possible)<sup>42</sup>, before attempting to provide supportive care over the telephone. Also pre- and post-surgery consultations at hospital sites provided opportunities for face-to-face consultations, especially for hospital-based RBNs. Additionally, telephone consultations may have been more common during follow-up phases as clients visited cancer services less frequently and thus could not 'piggy-back' face-to-face consultations. Similarly, the NBCC SBN Demonstration Project identified that telephone consultations enabled follow-up support to continue in the face of logistical challenges when rural residents returned home (SBN Project Team, 2000).

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<sup>42</sup> However, given the typically short time span during which to provide diagnosis phase consultations, many may not have been possible unless by telephone.



Interestingly, the *Private Hospital RBN Site* consultation delivery mode pattern varied strikingly from the other RBN sites, with almost mirror opposite patterns. This site utilised telephone contacts most heavily, with face-to-face contacts only similar to the other sites during follow-up one. It is possible the *Private Hospital RBN Site's* differing contact pattern resulted from fewer hours available in the role, and/or a less structured system for identifying clients. Thus, increased face-to-face consultations during the follow-up phases may have resulted from *Private Hospital RBNs* making telephone contact with women after learning of a patient's surgery, and scheduling face-to-face consultations for a future date which was typically post operation.

#### **6.2.2.2. Who Initiates**

Consultation initiation source demonstrates whether consultations were pre-arranged by RBNs, or requested by clients in response to their needs. More client-initiated consultations might also suggest the RBN was available and accessible to clients (perceived and/or actual). In this study, nurse-initiated consultations were more common than client-initiated across all treatment phases and RBN sites (with the only exception being 'other' consults for *Public/Private RBN Site*). Of all treatment phases, 'other' consultations were most likely to be client-initiated for the *Summarised RBN*. Client-initiated consultations at the first follow-up were notably higher than during other treatment phases. Similarly, the NBCC SBN Demonstration Project also reported client-initiated consultations highest during the 1 – 6 week post-operative treatment phase (SBN Project Team, 2000).

**Table 24: Consultation initiation source across Rural Breast Nurse Sites**

KEY:  
% (n)

Consultation Initiation Source Characteristic	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public / Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Nurse-initiated consultations (%) *	40% (360)	35% (113)	37% (149)	53% (98)
Client-initiated consultations	19% (170)	15% (48)	27% (110)	7% (12)
Nurse-initiated diagnosis phase consultation	22% (8)	18% (2)	22% (5)	33% (1)
Nurse-initiated pre-operative consultation	34% (33)	31% (8)	30% (14)	42% (11)
Nurse-initiated post-operative consultation	44% (80)	43% (22)	45% (41)	45% (17)
Nurse-initiated 1-6wks post-operative consultation	36% (73)	31% (30)	40% (26)	44% (17)
Nurse-initiated 6-10wks post-operative consultation	47% (35)	35% (12)	27% (3)	69% (20)
Nurse-initiated 'other' consultation	44% (110)	43% (32)	37% (53)	69% (25)
Client-initiated diagnosis phase consultation	3% (1)	0% (0)	4% (1)	0% (0)
Client-initiated pre-operative consultation	7% (7)	0% (0)	15% (7)	0% (0)
Client-initiated post-operative consultation	2% (4)	6% (3)	1% (1)	0% (0)
Client-initiated 1-6wks post-operative consultation	15% (30)	13% (13)	23% (15)	5% (2)
Client-initiated 6-10wks post-operative consultation	7% (5)	6% (2)	9% (1)	7% (2)
Client-initiated 'other' consultation	43% (109)	31% (23)	55% (78)	22% (8)

\*NOTE: percentages do not equal 100% as 41% initiation source data missing (374 of 904 possible)

Differences in consultation initiation source were observed across RBN sites. While the *Private Hospital RBN Site* demonstrated proportionally more nurse-initiated consultations across all treatment phases, the *Public/Private Hospital RBN Site* reported the highest percentage of client-initiated consultations across all treatment phases. It is possible that fewer and less regular hours of the *Private Hospital RBN Site* made RBNs less accessible for women to contact, and/or the perception of accessibility was diminished. In contrast, the *Public/Private Hospital Site's* centrally located office is likely to have facilitated client-initiated consultations when women were passing by her regularly staffed office for other medical

appointments. Thus, it is likely that client-initiated consultations reflect the accessibility of RBN services. This is explored further in the next two chapters.

In summary, the means through which contact is made and maintained influence the pattern of RBN supportive care provided, and possibly the outcomes received. In this study, delivery mode and initiation source was used to capture consultation delivery. Although face-to-face consultations were more common for the *Summarised RBN*, over one third of RBN consultations were provided over the telephone. Furthermore, all RBN sites utilised telephone consultations more than the NBCC SBN Demonstration Project. RBNs proximity to surgical and oncological cancer services appeared to increase the proportion of face-to-face consultations for the *Public/Private RBN Site*, however this was not always the case. Specifically, the *Community RBN Site's* high proportion of face-to-face and nurse-initiated consultations viewed in combination with the travel results, suggest *Community RBNs* scheduled consultations to meet clients face-to-face.

The findings also indicate that client-initiated consultations may be due to the accessibility of RBN services. Being the most centrally located within cancer services and regularly staffed, the *Public/Private Hospital RBN Site* had the greatest proportion of client-initiated contacts across all treatment phases. At the same time, the *Private Hospital RBN Site* with the least regular hours and close to surgical services only recorded the smallest proportion of client-initiated consultations. These findings, along with significant use of telephone contact, indicate the *Private Hospital RBN Practice* primarily provided scheduled telephone consultations.

### **6.2.3. Content – What is Discussed and Done**

RBNs aim to support the prevention, treatment, and management of a diverse set of problems or issues for their clients. Thus, the interventions provided by RBNs are complex, involving an array of activities and skills that are applied differently based on individual client needs. This section conveys what happened during RBN

consultations from the nurses' perspective, namely the domain emphasis and written resources and referrals provided<sup>43</sup>.

### 6.2.3.1. Consultation Domains of Emphasis

The RBN-perceived consultation emphasis may arise from greater expressed needs and/or assumed client needs. Moreover, emphasis may be in an effort to manage or treat an issue, or it may be to prevent or minimise a potential problem. This section presents the consultation emphasis for the *Summarised RBN*, and for individual RBN sites in Table 25<sup>44</sup>.

Some supportive care domains received greater emphasis during consultations than others. Domains most often emphasised by the *Summarised RBN* were Psychological, Health System and Information, and Physical and Daily Living domains. The Sexuality domain was selected least often as an area of emphasis. Table 25 shows how individual RBN sites demonstrated different patterns of consultation domain emphasis.

**Table 25: Mean supportive care domains of emphasis per consultation (n=904) n = m(SD)**

Supportive care domains of emphasis	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Psychological	0.79 (.95)	.86 (.78)	.76 (1.10)	.72 (.88)
Health System & Information	0.69 (.90)	.95 (.76)	.59 (1.04)	.45 (.69)
Physical & Daily Living	0.55 (.85)	.52 (.65)	.74 (1.05)	.18 (.46)
Basic	0.11 (.41)	.15 (.40)	.09 (.43)	.09 (.38)
Sexuality	0.05 (.23)	.07 (.28)	.00 (.07)	.10 (.33)

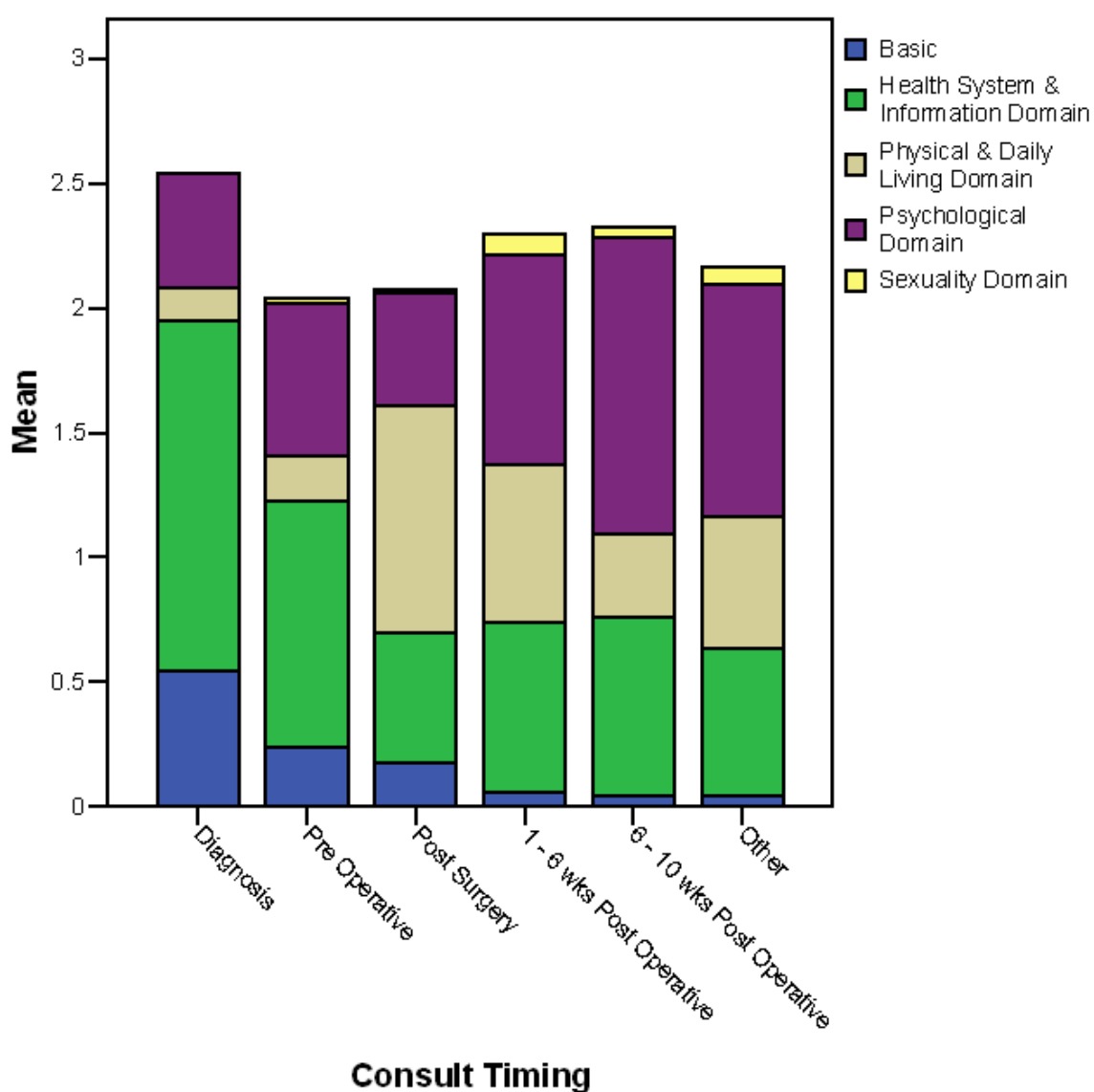
<sup>43</sup> This data is derived from the Consultation Logs (n=904) completed by RBNs for each eligible client's RBN consultation. Results are compared whenever possible to those presented by the NBCC SBN Demonstration Project.

<sup>44</sup> The NBCC SBN Demonstration Project did not present similar information for analysis.

Certain domains were emphasised to a greater or lesser extent by different RBN sites. The greatest consistency was in the Psychological Domain where all sites had a similarly large focus. In contrast, the Physical and Daily Living domain had the greatest disparity between sites. The Sexuality domain received the least emphasis. The *Community RBN Site* stood out for its significant emphasis on Health System and Information domain. This may have been due to the complicated healthcare system its clients were situated within. Moreover, RBNs reported emphasising different domains across treatment phases.

The *Summarised RBN* demonstrated different patterns of domain emphasis across treatment phases. That is, the pattern of consultation emphasis changed across time. Figure 9 displays the changes in domain emphasis across treatment phases for the *Summarised RBN*. Earlier visits were characterised by an emphasis on Basic items (i.e. introductions, contact details etc.), while this emphasis logically decreased over time. The diagnosis consultations had significant emphasis on the Health System and Information domain. Similarly, pre-operative consultations had a high emphasis on Health System and Information domain, and also an increased emphasis on the Psychological domain. Post-surgical consultations had the emphasis peak for the Physical and Daily Living domain. Post-operatively the Psychological domain was of primary emphasis, with Health System and Information domain emphasised next most often. Meanwhile, the Physical and Daily Living domain continued to decrease in emphasis. Although uncommon, the Sexuality domain was most often emphasised at the first and second follow-up or during 'other' consultations.

**Figure 9: Summarised RBN changes in domain emphasis across treatment phases**



Consultation domain emphasis peaked for Health System and Information during diagnosis, post-surgically for the Physical and Daily Living domain, follow-up one for Sexuality items, and the Psychological domain at follow-up two. Meanwhile, the Health System and Living domain was the most consistent through time.

NBCC Demonstration Project SBNs also noted women's changing consultation needs over time, although different descriptors were used (SBN Project Team, 2000). Similar to this study's results, 'psychological symptoms' were consistently reported

as a high needs throughout treatment phases. Additionally, other needs demonstrated similarities to these results<sup>45</sup>.

### 6.2.3.2. Written Resources and Referrals

Two key activities of the BN are coordination of care and information provision. These activities are supported by the provision of written resources and referrals. This section details how often RBNs provided various written resources and referrals during this study. A total of 588 written resources and 245 referrals were provided by RBNs during the one year of data collection<sup>46</sup>. Table 26 lists the mean written resources provided and referrals given per consultation by RBN sites.

**Table 26: Mean written resources and referrals provided per RBN consultation**

mean # (variance)	<i>Summarised RBN</i> (n = 904)	Community RBN Site (n=319)	Public/Private Hospital RBN Site (n=401)	Private Hospital RBN Site (n=184)
written resources	.65 (2.214)	.68 (1.280)	.86 (3.709)	.15 (.246)
referrals	.27 (.382)	.40 (.550)	.16 (216)	.28 (.398)

#### 6.2.3.2.1. Written Resources

Information is typically provided in a combination of verbal and written forms. The quantity and type of written materials distributed to women were recorded by RBNs. The *Summarised RBN* distributed a mean .65 written resources per consultation. Women were provided with written resources during almost a quarter of all RBN consultations, including 20% of consultations receiving one to four resources, and 4% receiving five to ten items. Table 27 presents the percentage of RBN consultations when various quantities of written resources were

<sup>45</sup> Throughout treatment phases 'psychological symptoms' was consistently one of the top two areas of need, while during diagnosis and pre-operative phases 'surgery' was the other primary issue, post-operatively 'general treatment information' needs were important, and during follow-up phases needs were also around 'problems after treatment'.

<sup>46</sup> Written resources and referrals were recorded by RBNs within Consultation Logs.

provided. The numbers presented in Table 27 represent the resources per consultation.

The quantity of resource distribution varied across RBN sites. *Community RBN Site* had the highest percentage of consultations distributing information, followed by the *Public/Private Hospital RBN Site*. The *Private Hospital RBN Site* distributed significantly fewer written resources, with written materials being provided to clients in only 10% of consultations. The mean written resources provided followed a similar pattern with the *Public/Private Hospital and Community RBN Sites* having the higher mean resources provided per consultation than the *Private RBN Practice*. The *Private Hospital RBN Site* provided a much lower mean of written resources per consultation. Thus, the *Public/Private Hospital and Community RBN Sites* provided more written resources more often than the *Private Hospital RBN Site*.

**Table 27: Quantity of written resources provided to women by Rural Breast Nurse Sites during consultations**

Resources	<i>Summarised RBN</i> (n = 904)	Community RBN Site (n=319)	Public/Private Hospital RBN Site (n=401)	Private Hospital RBN Site (n=184)
Zero	76%	66%	77%	90%
1 - 2	14%	22%	10%	9%
3 - 4	6%	11%	5%	1%
5 - 10	4%	1%	9%	0%
10<	0%	1%	0%	0%

It may be that consultations during early treatment phases or emphasising Health System and Information domain were associated with higher rates of information provision. Thus, as the *Public/Private RBN Site* consulted with relatively more clients at diagnosis and pre operatively, the site reported the highest rates of information provision. Also, as the *Community RBN Site* had a strong emphasis on the Health System and Information domain, it would then follow that a large amount of both verbal and written information was provided.



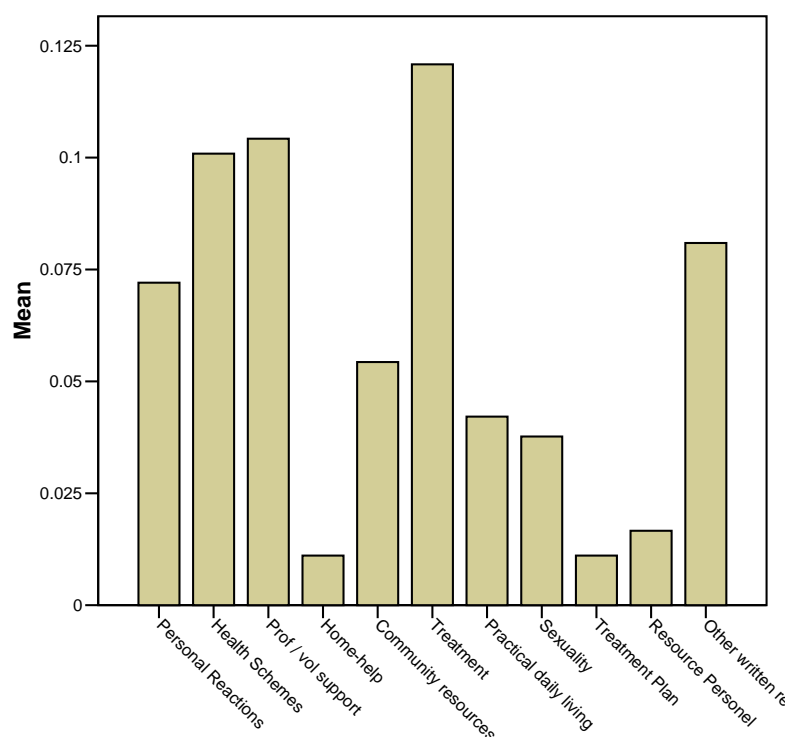
It is also possible that other services provided clients with relevant written materials, such as the surgeon or diagnostic centre. Or it could be that the add-on *Private Hospital RBN Site* had less written resources at their disposal, whereas the *Community* and *Public/Private Hospital RBN Sites* may have stocked the written resources as a regular part of their core business. This effect could have been exacerbated by the lack of dedicated office space available to store materials at the *Private Hospital RBN Site*.

The most common type of written resources provided by RBNs were pertaining to treatment, professional / volunteer support, and health schemes followed by resources discussing personal reactions. 'Other' information topics also proved prevalent<sup>47</sup>. Figure 10 displays the mean number of various written resources provided by the *Summarised RBN* per consultation. Furthermore, individual RBN sites distributed different types of written resources.

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<sup>47</sup> The range of 'other' information resources provided was extensive; these most typically were to do with arm exercises or lymphoedema prevention, general breast cancer information booklets or kits (e.g. All About Early Breast Cancer or the My Journey Kit), prosthetics or support garments, and family history.

**Figure 10: Summarised RBN mean written resources provided across category topics**



The most common written resources distributed varied across treatment phases. The greatest proportion of clients received written information from RBNs during post-surgical consultations, whereas the least resources were received during follow-up two and 'other' consults. These findings likely reflect RBNs perceptions of what would assist clients across their cancer journey. For example, treatment and personal reactions dominated the diagnosis to post surgery time points, while information about professional and volunteer support was most prolific post surgery and at the first follow-up.

#### 6.2.3.2.2. Referrals to Other Services

RBNs providing referrals for women are an indicator of their coordination of care, or the linking of women to other pertinent services to improve their cancer journey. The quantity and source of referrals were recorded by RBNs. The *Summarised RBN* provided a mean of .27 referrals per consultation. RBNs referred women to

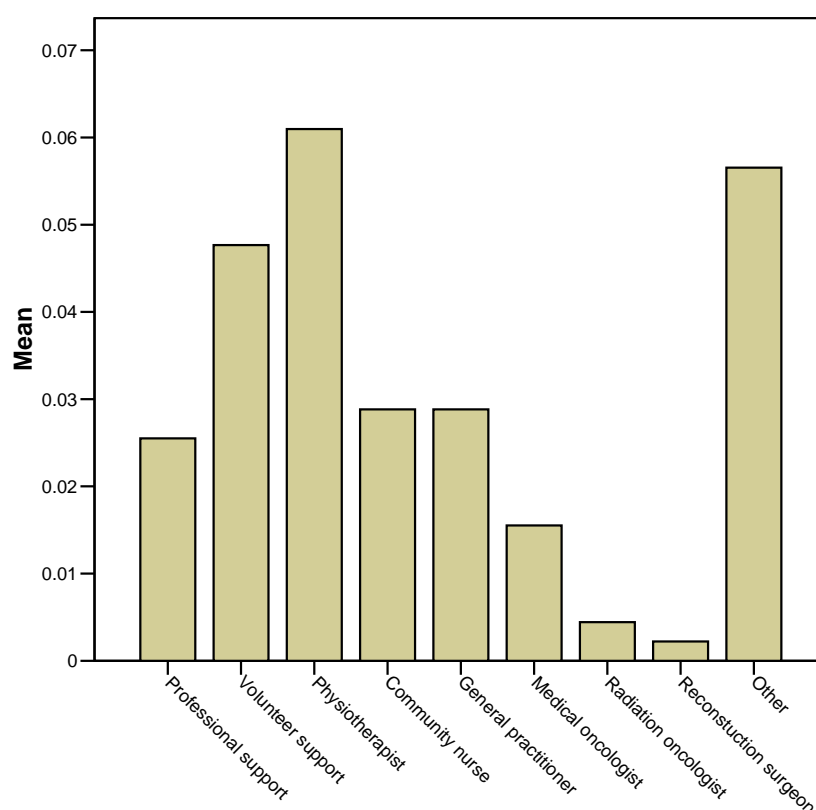
physiotherapists most often<sup>48</sup>, followed by volunteer support. Importantly, ‘other’ referral sources also ranked highly. Community nursing, the general practitioner, and professional support were the next most common referral sources. Mean referrals per consultation to various referral categories for the *Summarised RBN* are presented in Figure 11.

RBN sites demonstrated diversity in the quantity and location of referrals provided. The *Community RBN Site* reported the highest mean referrals per consultation, followed by the *Private Hospital RBN Site*, and the *Public/Private Hospital Site* (.40, .28, and .16 respectively). RBN sites also demonstrated different referral patterns across categories. Notably, the *Community RBN Site* gave the most referrals to professional support, possibly as a psychologist was available in the region while not generally in other regions. It may be that fewer RBN referrals were due to already established referral networks (i.e. clients were being referred by others), which may have been the case in the *Public/Private Hospital RBN Site* having been established for >10 years. Yet it is also possible that lower referrals were due to fewer referral options available.

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<sup>48</sup> Physiotherapy referrals were likely for lymphoedema prevention and/or management.

**Figure 11: Summarised RBN mean referrals across referral categories**



Also, referral categories differed across treatment phases. Volunteer support referrals were most prominent before surgery. Physiotherapy referrals were the most prominent service referred to post surgically and at follow-up one, and community nursing and general practitioner referrals were also prominent during that time. It is likely RBNs were responding to specific issues - either expressed, observed, and/or anticipated needs – with their referrals to other services.

The *Summarised RBN* referral profile is generally consistent with that of the NBCC SBN Demonstration Project, although important differences exist (SBN Project Team, 2000). While the most common services for referral were similar (e.g. physiotherapist, breast cancer support group, community nurse, and general practitioner), the NBCC Project reported higher proportions of referrals to professional support roles (e.g. social workers and psychologists). Furthermore, RBNs provided proportionally fewer referrals to the most commonly referred

services. Additionally, RBNs instigated referrals to volunteer support slightly earlier, and physiotherapy slightly later<sup>49</sup>.

In summary, within this study RBN consultation content was described by RBN perceived consultation emphasis, and written resources and referrals provided. The primary areas of emphasis for the *Summarised RBN* were the Psychological, followed by the Health System and Information, and Physical and Daily Living domains. The primary areas of emphasis varied for different RBN sites. The *Community RBN Site* focused most heavily on Health System and Information and Psychological domains, and the *Public/Private Hospital RBN Site* had the highest mean emphasis on Physical and Daily Living domain. Meanwhile, of all the practices the *Private Hospital RBN Site* was most likely to emphasise the sexuality domain. Moreover, patterns of consultation domain emphasis varied across treatment phases.

The quantity and type of written resources and referrals provided varied for RBN sites. The *Community RBN Site* consultations were most likely to include written information provision, yet the *Public/Private Hospital RBN Site* provided the greatest quantity of resources per consultation. The *Private Hospital RBN Site's* level of written information distribution was dramatically lower. Clients engaged in post surgery consultations were most likely to receive written resources than at any other treatment phase. RBNs referred women to various sources, and referral patterns varied across treatment phases. The most common referrals were to physiotherapy and volunteer support. The major difference between RBN referrals patterns and that of the NBCC SBN Demonstration Project was the smaller proportion of referrals by the RBN to professional support.

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<sup>49</sup> The NBCC SBN Demonstration Project did not collect referrals to other community services, thus a comparison is not possible in this area.

### 6.3. Summary of Sites

Importantly, RBN sites revealed a diversity of ways to provide support to women. Notably, two patterns emerged. Hospital-based RBNs had more consultations per client of a shorter duration whereas community-based RBNs had fewer consultations per client but they were of a longer duration, often travelling to consult face-to-face. Below are quantitative descriptions of the three RBN sites within this study.

#### 6.3.1. Community Site

Two nurses within the *Community RBN Site* fulfilled 30.6 hours per week, which was the greatest time investment in an RBN service within this rural study. As this catchment area accounted for approximately 50% of the cases state-wide, it was logical this area would have the largest investment in RBN hours. The *Community RBN Site* also had the most nursing hours per consulting client (12.9 hours), accounting for all hours, not only those in direct patient support. Not surprisingly, this site was most involved with clients post-operatively. *Community RBN* clients most commonly received consultations post-operatively, specifically during the post-operative and follow-up one treatment phases (59% and 68% respectively).

The *Community RBN Site* enacted a different approach to breast nursing than did the other RBN sites. Although the *Community RBN Site* had the fewest mean consultations per patient (3.2), the consultations lasted longer (mean 46 min), and the greatest proportion of face-to-face support time (78%), as compared to other RBN sites in this study. The *Community RBN Site* also had the highest proportion of time spent on travel (13%). The results portrayed the *Community RBN Site* travelling to have longer face-to-face consultations. As the *Community RBNs* were not on site at the major treatment centres, they either travelled to treatment centres and/or clients' homes. The duration of telephone consultations were also the highest of all RBN sites (24min), suggesting telephone consultations were also of a relatively engaging nature.

*Community RBN Sites* consultations emphasised the Psychological, and even more so the Health System and Information domain more than any other RBN site, and this emphasis remained high across the treatment trajectory. Consistently, written resources were provided during approximately one-third of consultations, and referrals were markedly more common for the *Community RBN Site* (.40) than others. Increased referrals might have been due to increased referrals options (including both professional and volunteer services) as well as RBN knowledge of those options. One key referral source available only in this region was a publicly-funded psychologist for cancer patients.

### **6.3.2. Public/Private Hospital Site**

The *Public/Private Hospital RBN Site* was the only RBN role with a long standing history in Tasmania. Thus, the RBN was established in her professional skills, and in the local health system. The established nature of the service, and the physical proximity to all cancer services in the region, likely enabled the RBN to focus a significant amount of time into patient-related duties (70%), the highest proportion of all RBN sites. For example, as the RBN did not need to spend time introducing the role to professional colleagues, her time was solely directed towards supporting women, and thus was more 'efficient' in directing hours towards addressing clients' supportive care.

The one RBN was situated within the major public hospital in the region, which was co-located with the only private hospital. While a mean 14 hours per week was invested in the role, given the smaller catchment population, this amounted to 11.3 nursing hours per consulting client. Although this site's patients came from a diverse rural area, the region's cancer treatment locations were in very close proximity to the RBN's established office. Thus, the layout of services<sup>50</sup> led to client-initiated consultations in the RBN's office, and the RBN could easily visit

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<sup>50</sup> That is, the RBN's offices proximity to the region's treatment wards and consultants' appointment rooms.

treatment wards. Therefore there was a high degree of availability of the RBN to clients, and accessibility of clients to the RBN. These features were reflected in this site's results. Specifically, the *Public/Private Hospital RBN Site* had the highest proportion of face-to-face consultations (70%), and the highest number of consultations per client (mean 6.6), and the highest percentage of client-initiated consultations (27%) as compared to the other RBN sites in this study.

Significantly, the *Public/Private Hospital RBN Site* was most likely to consult with clients at all points in the treatment trajectory (except pre-operatively). The highest proportions of clients receiving consults were at post-operative and follow-up one treatment phases (both with 84%). Importantly, 39% of the clients received consultations at diagnosis, the highest of all RBN sites in this study. It appears this site's close proximity to all of the region's cancer treatment services, and the provision of an allocated office that was staffed by the RBN full time (even if the time was split between breast nursing and stomal therapy) were influential in the frequency and timing of consultations.

The consultation emphasis for the *Public/Private Hospital RBN Site* was the most evenly distributed across the three major domains, namely Psychological, Physical and Daily Living, and Health System and Information, as compared to the other RBN sites. This RBN was most likely to emphasise the Physical and Daily Living domain as compared to the other RBN sites. It is interesting to note that although the *Public/Private Hospital RBN Site* did not record a consultation emphasis for sexuality, the provision of information on this topic was relatively high.

The *Public/Private Hospital RBN Site* clearly took a lead role in information provision, with the RBN providing the highest number of information resources (mean .86). Larger quantities were provided as compared to other regions (9% of consultations saw women receive >5 written resources). Conversely, the fewest



referrals were provided by this RBN<sup>51</sup>. This suggests that the RBNs established role was to provide written resources, yet referrals were either not available (i.e. services did not exist), or made by others in the system.

### **6.3.3. Private Hospital Site**

Two private hospitals engaged current staff members to add-on RBN duties to their other roles; one Surgical Ward Nurse, the other a Discharge Planning Nurse. These two sites were combined for analysis, and somewhat artificially termed the *Private Hospital RBN Site*. The RBN positions were new to the region, being the first ones ever, yet were generally limited to supporting privately-insured women who were clients of their respective hospitals.

The *Private Hospital RBN Site* demonstrated the smallest proportion of time in patient-related duties (38%), the fewest hours worked per week (6.2 hours), as well as the fewest nursing hours per client (6.2 hours) as compared to other RBN sites. Although consultation durations were similar to the other hospital site (mean 20-33 min), the *Private Hospital RBN Site* reported the highest proportion of consultations delivered over the telephone (43%). The *Private Hospital RBN Site* distributed much fewer written information materials than the other RBN sites (mean .15). This may have been due to the lack of an established office or regular hours, and/or others already providing information to clients.

The *Private Hospital RBN Site's* most common consultations were at pre- and post-operative phases. Interestingly these were significantly more likely to be over the telephone. The *Private Hospital RBN Site* had the highest proportion of clients who received consultations during the pre –operative phase (69%) when compared to the other RBN sites. Client-initiated consultations were the least common for the *Private Hospital RBN Site* (7%). RBNs addressed and emphasised the Psychological

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<sup>51</sup> It should be noted this region likely had the fewest professional and volunteer support services, although this study was unable to confirm this.

domain more often than other domains, and was most likely of all RBN sites to emphasize the Sexuality domain.

## **6.4. Chapter Conclusions**

This chapter demonstrated diversity across RBN sites in terms of how RBNs go about their role. Specifically, the results provided a picture of overall rural breast nursing practices, and the consultations provided to women. Broadly speaking, rural caseloads are smaller than urban. Yet, the mean nursing hours per patient may be similar for rural and urban BNs, as RBNs tended to work fewer hours. Furthermore, there are broad similarities in how urban and rural BNs distribute their time between duties. This includes a large proportion of time spent on non-patient related duties. However, RBNs devote proportionally more time to travel and telephone support.

The findings convey diversity across RBN sites in terms of how consultations are provided, specifically their dose, delivery, and content. A significant proportion of consultations occurred outside of, or additional to, the designated treatment phases (43% overall, mean 1.9 / client). Although RBN consultation timing diverged from the clinical pathway of the NBCC SBN Demonstration Project, the total number of RBN consultations per client was remarkably similar. RBN clients were most likely to receive consultations post operatively and at follow-up one than any other treatment phase, whereas diagnostic consultations were least frequent. RBN consultations averaged 34 minutes, while their length generally decreased over time. Face-to-face consultations were markedly longer, yet their initiation source did not impact consultation length (differing from the NBCC Project).

RBNs consistently used telephone support more often than reported within the NBCC SBN Demonstration Project. Although consultations were often delivered face-to-face, one-third of RBN consultations were delivered over the telephone. Differences in delivery mode and initiation source were also observed across RBN sites. That is, RBN sites used different combinations of face-to-face and telephone

consultations to make and maintain supportive contact through women's journey. These differences may be explained by RBNs proximity to other cancer services, along with varying RBN approaches.

Additionally, RBN sites had different approaches to travelling for face-to-face visits, and utilising telephone consultations. The data provide a picture of the *Community RBN Site* travelling to enable face-to-face consultations with women whether they were in hospital or at home, thereby utilising the freedom of the position and combating their physical isolation (non-cancer specific service base). Hospital RBN sites spent proportionally less time in travel and more time providing face-to-face support than the *Community RBN Site*. In particular, the *Public/Private Hospital RBN Site* attained 10% greater face-to-face consultations (75%) than both the *Private Hospital Site* (65%) and the *Community Site* (64%).

During consultations, certain domains were more often the focus of discussion, namely Psychological, Health System and Information, and Physical and Daily Living items. Yet, RBN sites demonstrated different patterns of domain emphasis. As with consultation emphasis, referrals and written resources distributed varied across treatment phases. Written resources were most often provided during post-surgery consultations. Referrals were most commonly to physiotherapy and volunteer support. RBNs reported proportionally fewer referrals to professional support than the NBCC SBN Demonstration Project.

The findings of this chapter raise the question of what factors determine what activities an RBN undertakes generally, and within consultations. In essence, why does the RBN do what she does, and what factors influence these actions? In the next chapter (Chapter Seven), these questions are explored with the findings from semi-structured interviews with participating RBNs.

## **Chapter Seven: Rural Breast Nursing Practice –Nurses’ Insights on Intervention and Nurse Influences**

The purpose of this, and the next, chapter is to present RBNs’ descriptions of their breast nursing practices, and the many influences on their breast nursing practices and client outcomes. The following sections detail the findings from semi-structured interviews with RBNs. How these findings were drawn from qualitative interview data was previously described in Chapter Four<sup>52</sup>. To recap, six RBNs were interviewed with five nurses representing the three RBN sites described in the quantitative results of Chapters Five and Six, and one new Community RBN from within the previous Private Hospital RBN area. These findings address the sub-question: *How do RBNs describe their practice, and what factors influence their practice?*

The generic nursing conceptual intervention framework was applied to interpret and make sense of the data whilst using iterative thematic analysis (Sidani & Braden, 1998). Four elements influence breast nursing practices and outcomes for women - namely characteristics relating to the intervention, intervener, client, and setting. The results of this chapter describe how these characteristics interact and impact on breast nursing practices and psychosocial outcomes for women with breast cancer. The RBNs detailed the influence of the woman, nurse, processes of care, and the context on their capacity to support women through their breast cancer journey.

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<sup>52</sup> The emphasis within quotes, depicted with underlines, is drawn directly from the RBNs themselves.

These qualitative findings are presented in this, and the next chapter. The notations indicating individual nurses in this and the next chapter (e.g. RBN1) are specifically *not* linked to the RBN notations in Figure 4 (e.g. S1 and NW1) to provide confidentiality to participating RBNs. The qualitative findings of RBNs' perceptions of nursing practices and the influences on these and client outcomes are reported in two sections of this chapter. The first section describes the intervention processes of care that are intended to positively influence client outcomes. The second section details RBNs' influence on nursing practices and client outcomes, namely the intervener's professional and personal characteristics.

## **7.1. Processes of Care Influencing Practices and Outcomes**

This section describes the processes of care RBNs described using to support women with breast cancer. It is recognised that breast nursing practices vary to fulfil women's diverse needs and experiences. Indeed diverse nursing practices were described quantitatively in Chapter Six. This section expands on the previous quantitative findings by providing qualitative data about what RBNs do, and how they go about their work.

The interview data shed light on the complex and multifaceted nursing practices of RBNs. The nursing interventions detailed in this section correlate with the "processes of care" described in the theory-driven approach to evaluating nursing interventions (Sidani & Braden, 1998). Two levels of nursing practices are described: 'micro' meaning focused on the patient and or couple, and 'meso' meaning interfacing with healthcare providers and/or the healthcare system.

The nursing interventions described by RBNs were classified during the analysis as: holistic assessment, providing a pivot point, linking, providing information &/ translating, dealing with emotions and coping, supporting decision-making, filling the gap, advocating, client finding, collaborating, and peer support. The RBN processes of care and their levels of practice are displayed in Table 28, and described in the below.

**Table 28: Levels of nursing interventions undertaken by Rural Breast Nurses**

Nursing Interventions	Levels of practice undertaken	
	Meso	Micro
Holistic Assessment		X
Providing a Pivot Point		X
Linking		X
Providing Information &/ Translating	X	X
Dealing with Emotions & Coping		X
Supporting Decision-Making		X
Filling the Gap		X
Advocating	X	X
Client Finding	X	
Collaborating	X	X
Peer Support	X	

### 7.1.1. Holistic Assessing

RBNs described holistically assessing their clients throughout the care continuum. They utilised high level assessing and interpersonal skills throughout their care interventions, whilst embodying a client-centred care approach. Furthermore, they attempted to engage women to participate in their care, by requesting their input to the RBN's care.

RBNs illustrated how they assessed women on their emotional and physical status and support resources to determine the RBN care plan. The assessments were described as holistic in nature, including the woman's responsibilities at home or outside, and her support networks. This was depicted as a constantly evolving plan based on continual re-assessments and changing needs.

*"...each woman is very very different, so by gathering as much information about a woman in your first discussion with her ... I can then decipher whether this lady needs to see me now or this lady is happy to just to talk to me over the phone. ...I ask them about their working lives, their family life, whether they have a carer, whether they*

*feel supported, and whether they have someone to talk to, other than healthcare providers. ... So by assessing it helps with my decision making about how I will deal with that lady...” RBN1*

The interventions RBNs engaged in were generally described as client-centred. RBNs described letting the woman’s needs and her own individual journey drive their interventions. Clients were invited to participate in the plan, and asked to provide information about their needs, and desires for information. The nurses described using information as a means of support, and to allay fears. RBNs portrayed themselves as actively engaging women to gain information on their individual needs.

*“...so I do try and get them to be my guide to their needs, because I think it is very important that we don't assume that we know what they need to know.” RBN3*

The nurses portrayed themselves as being accessible for clients to contact, and open to discuss whatever issue the client may need discussed. They expressed themselves as seeing the woman as a whole, and developing rapport with her. The RBNs felt they often brought up or at least opened the opportunity for emotional and sensitive topics such as sexuality and relationships.

### **7.1.2. Providing a Pivot Point**

RBNs illustrated their central position in assisting women to manage their experience with breast cancer. By viewing a woman as a whole person, placed in her own personal circumstances, the RBN was able provide support for a range of her needs, rather than simply addressing the disease. The RBNs described being an ever-present stabilising centre (the centre of the wheel) as women linked out and back in again with various providers and services (the spokes of a wheel) for treatments and different needs.

*“So we spend a lot of time talking about their treatment choices, their diagnosis, who they see for what problem, where each medical person comes in, because breast cancer is such a multi-disciplinary approach. They see so many healthcare providers in a short period of time, so our job is to be that pivot point of contact that can keep the whole system working for the woman, so she's not lost in it.” RBN1*

One nurse described how at each step in their treatment or experience, the RBN and woman would check back in with one another.

*“It really kind of fits in around their progress through their treatment, so every time they have a significant change in the treatment plan I speak with them, so we can talk it through.” RBN1*

The nurses conveyed the image of being a ‘tour guide’ as they prepared women for what to expect of each stage or step. One RBN expressed that she could “*map the way for them*” (RBN3). RBNs did this by explaining what treatments will entail (e.g. symptoms and processes), how to prepare, and tips from someone ‘in the know’. For example, RBNs provided women with contacts for appropriate and affordable accommodation options, and directing them to the government travel support program.

A key activity for RBNs in their role as the pivot point is preparing women for their upcoming appointments with specialists, as well as debriefing afterwards to consolidate understandings and clarify a woman’s next steps.

*“I will often talk to them post-op at home, so they can talk through any questions they might have for their surgeon when they go in for that post-op surgical review. And then I always say, ‘When you see your surgeon, give me a call back, and so we can clarify what he said to you.’ ” RBN1*



Nurses perceived that by supporting women to prepare for their interactions with specialists, the specialist consultations were more constructive and informative for women, leading to a more positive experience.

*“They're armed with a bit of information, so their visits with oncologists or their professionals are very constructive.” RBN1*

Part of the role of being a pivot point was an RBN making herself available and accessible to women. RBNs conveyed their availability to women, and encouraged women to call upon them if they encountered a problem or generally needed the RBN's support. RBNs also expressed

*“I give them my contact details in hospital just so that if there's a big glitch they have got somebody to phone.” RBN4*

In order for the RBN to be a pivot point, RBNs expressed their need to 'sit at the interface' of services and organisations. This often meant crossing traditional organisational boundaries. Sitting at the interface and communicating and moving across sectors and services was consistently described as a desirable trait or ability of an RBN. By sitting at the interface, this meant accessing and linking with public and private systems, and across supportive and healthcare services, and hospital and community settings.

*“She [the RBN] is able to sit at that interface and come into the private and into the public and wherever she needs to be.” RBN5*

This interface role required RBNs to interact and communicate with clients, nursing and community staff, specialists and supportive services, and manoeuvre through all health systems with confidence, ease, and insight.

*“It's not just about holding a hand. It's not about that. It's about manoeuvring through the healthcare system and dealing with other*

*professionals, dealing with really complex emotions and stuff like that.” RBN5*

### **7.1.3. Linking**

Another process of care identified was linking. Although similar to the pivot point care process, a subtle nuance necessitated a different intervention category for linking. Linking interventions are about referral out to other services and resources whereas providing a pivot point is about being a central figure upon which the woman can depend, and continue to return to for support and direction.

Nurses described their role as ‘the link’ by connecting women with resources and other services to address health and or prevent ill health. Their referring activity was seen as an important RBN intervention. Multiple RBNs described their need to refer to other services as opposed to have all the answers or relevant skills within their role or capacity.

*“I see the breast care nurse as a link, I don't see them as wholly and solely all support. It's all those other things that go with it.” RBN5*

Although RBNs were often quite confident and knowledgeable with most aspects of care, they conveyed respect for other specialists’ ability to provide greater detail, and thus they readily referred women when needed.

*“I feel quite comfortable broaching all these subjects, I think that I'm there also in a coordinator type role, so that if I think that I'm getting out of my depth I know exactly who to refer them to for a higher level, and I think that's really important. I don't see myself as being a jack of all trades and can't be absolutely into everything, although I know who to contact.” RBN6*

Women were linked into appropriate services and schemes by nurses who provided the relevant details, negating the need for women to track them down for themselves.

*"I tell them who they can actually go and talk to about getting the forms filled out and patient travel assistance, and all that sort of stuff."*

RBN3

Linking interventions often combined with the provision of information as discussed in the next section.

*"I've got the information here, so that they don't have to go searching for it." RBN3*

One RBN described empowering women to seek and or access information for themselves rather than providing everything for her.

*"Rather than actually providing all the information, once again I was more or less trying to direct the women as to where to find that information for themselves." RBN2*

#### **7.1.4. Providing Information or "Translating"**

RBNs used the terms 'translator' and 'sifter of information' to describe their care processes in informing or teaching women about their disease and treatment. This was a central activity conveyed by all RBNs.

*"The biggest thing I do for women is explaining to them what their pathology results mean and what it will mean in terms of ongoing treatment." RBN6*

The immense magnitude of breast cancer information materials necessitated RBNs 'sift through' materials to present that most appropriate information tailored to each woman.

*"I've felt that my role there was to ... encourage them to look at themselves and find the information that was actually useful to them and disseminate some of that information." RBN2*

One nurse depicted the challenges women face to take on board information at stressful times. She attempted to mitigate this situation by providing written information for the woman and her support network to review at a later time.

*“... Giving them verbal information but then backing it up with written information for them to then take it away...” RBN3*

Staging or timed information provision was portrayed as beneficial rather than overwhelming women with a pile of information at the beginning. To guide their information provision, nurses described themselves eliciting information preferences from women.

*“I ... open a conversation with a client asking where they're at and how much information, what kind of person they are, do they like to read a lot, or do they like to know a little or a lot.” RBN1*

*“Everybody has a right to the information that they want. Whether that be absolutely nothing, or whether that be absolutely everything, or somewhere in between, which is where the majority of people sit.” RBN3*

RBNs consistently described the woman and her needs as the driving force behind the discussions that were had and the information that was provided. The power and control was placed squarely in the client's hands to determine what was discussed.

*“From the first time when they come in ... I say to them that I am to be guided by them...” RBN3*

One nurse described giving clients' the responsibility to ask the RBN for more information, or to tell them if they were 'out of bounds'.

*“ ‘If there's something that I don't talk about or there's something that I start to talk about that you don't want to talk about, then it's your responsibility to highlight that fact for me.’ ” RBN3*

RBNs described using simplified accessible descriptions for treatments and biological processes to assist women's understanding. For example, one nurse described oestrogen's effect on a hormone sensitive breast cancer this way:

*“I'd always use the analogy, it is like putting dynamic lifter on the garden, it makes it grow.” RBN3*

Nurses described supporting women to understand and work through the confusing discrepancies in specialists' feedback on what would be 'the best' course of treatment for her.

*“...sometimes what seemed to happen is that the women would go from surgeon to an oncologist and the (radiation) oncologist would say something different to the surgeon, and ... then they might go to the oncologist that administers the chemo and he might say something different to this, and it was really difficult to juggle, to try and sift through sometimes why one said something different to the other, and trying to explain to the women why there is the variations, ... and that at times was really tricky.” RBN5*

#### **7.1.5. Dealing with Emotions and Coping**

Dealing with emotions and coping was a consistent and underlying theme in RBNs description of their care. RBNs described engaging with women on an emotional level in an attempt to assist them to address and manage their complex and intense emotions. Nurses aimed to increase or enhance women's capacity for self-care and coping. RBNs described themselves dealing with complex and intense emotions *“right from the beginning and all the way through”* (RBN1).

The nurses explained how they fostered an environment for women to express their feelings, a characteristic they believed was not typically provided by other healthcare services. One nurse recounted a GP's positive feedback about a shared client's experiences in being able to express herself freely with the RBN.

*"I got feedback that it was really good and she [the patient benefitted from] - just that ability to go Blah, that's all. The GP can't spend an hour for someone to go Blah." RBN5*

Nurses described encouraging women to care for themselves, by taking time to heal and to ask for help. One nurse explained this required them to convey both knowledge and 'permission'.

*" 'This is not a time for you to go home and get on with your life, you've got some more of the journey to go. You've got to go home and let yourself get better.' And so it's giving them - one the knowledge that they need to do that, but most importantly giving them the permission..." RBN3*

Nurses described the importance of the RBN's capacity and willingness to address the emotionally sensitive issues that other healthcare providers apparently did not address, but were central to women's own experiences and distress. For example, discussing sexuality issues:

*"I still don't think the broader healthcare team get this right. I think the minute you open up discussions about sexuality with women they sigh and think, 'Thank you. Good, someone's spoken to me about it.' " RBN5*

Tapping into women's own coping strategies was described as a means to assist women to support themselves, and improve their coping attempts. RBNs helped women to reflect on what strategies worked for them in the past.

*“If they were in real crisis ... or stuck in that aspect of feeling completely hopeless and overwhelmed, and to try and get them to tap into what strategies ... worked in the past and what hasn't, and have you tried this, and maybe ... to understand - to try and quickly understand what strategies would work for them.” RBN5*

RBNs expressed the importance of acknowledging the feelings and challenging emotional reality for each individual woman. The nurses acknowledged women's emotions and fears as real and understandable given their circumstances.

*“Trying to reassure them that every headache they have is not a brain tumour, but at the end of the day it was difficult. It was difficult to reassure them - you can give them stats, but stats don't mean anything ... [they feel] that one person, that's going to happen to me.” RBN5*

Nurses engaged in this emotional communication and engagement with individuals and/or as a couple when appropriate. All RBNs mentioned working with husbands or partners at times too, and generally presenting an inclusive service, although the vast majority of consultations were with the client only.

RBNs were careful not to describe their role as 'counselling', instead stating counselling was an intervention for mental health specialists such as counsellors or psychologists. They were clear that women with high needs required referral to those with specialist skills in mental health.

*“Our brief is to be there for women from a nursing perspective and not a counselling perspective, so whilst we help with coping and emotional needs we don't help in a clinical way... ” RBN1*

A few RBNs described supporting women through the emotional repercussions of disturbing consultations or interactions with other healthcare providers. One nurse described this as “mopping up” after other healthcare providers or services.

*“There are certain doctors ... that are very insensitive, and I think they treat women appallingly... We can deal with the emotional repercussions from that, and perhaps the anger that's produced by women.” RBN6*

#### **7.1.6. Supporting Decision-Making**

RBNs described themselves as supporting women to make decisions about their treatment and care. From their descriptions, it was clear RBNs were combining their skills in working with emotions and their knowledge of the cancer choices to assist clients to navigate their emotions and acquire information and understandings to enable them to make health related decisions.

A few RBNs described a technique whereby they encouraged women to project into the future in an effort to move them beyond the overwhelming feelings and anxiety of the present.

*“They're making decisions based on fear, anxiety. All those things are coming into play, so its important to be able to try and talk them through that then get them to take that path and imagine what it is going to be like in six months time. ... so I try and get them to put themselves in front of the mirror, standing there with no clothes on, imagine how you're going to feel when you look at yourself and your breast is gone. ... I think it is important that they're taken past the point where they are now and told, ‘Just think about how it is going to be then, because your thoughts, and your feelings, your emotions are all going to be so much different then.’ ” RBN3*

One RBN described how by letting women touch and hold prosthesis options, they were better able to make decisions about what might work best for them.

*“I think it is really important what they have a look at a prosthesis and the things that are available there, so I had my little trusty kit that*



*comes out so that I can show women look, this is what a prosthesis looks like and let them hold it, feel the weight of it, have a look at the bras, and that sort of thing. Because again all of that can help, I think, help them understand and know for their decision-making.” RBN3*

RBNs explained how they were able use their insider information and/or knowledge of the landscape of providers and services to support women to make decisions. One circumstance where RBNs assisted their clients’ decision-making was when women were deciding on which specialist to utilise.

*“We talk about the oncologists that are available, and who might work better for them, if they wanted a female or a male, if they want a very straight-shooting oncologist. I do talk about – without any personal preference - what everyone is like...” RBN1*

Multiple RBNs described how some women ask RBNs to make decisions for them. While this puts the nurse in an awkward position, RBNs attempted to steer women appropriately while leaving the decisions in the women’s hands.

*“...that's a question that a lot of people say to me, "Who should I see?", or, "What should I do?" And I think you can only - it's not our position really, ethically, to say one doctor's better than another, but sometimes you can just sort of help, steer people in the right direction.” RBN6*

#### **7.1.7. ‘Filling the Gap’**

‘Filling the gap’ was a recurrent theme in the RBNs’ descriptions of their care processes. These activities were about doing things that other healthcare providers were thought to have or expected to have done, but simply did not happen or were not happening. The activities were often around the provision of information and the enhancement of understandings.

*“One thing I've realised in this job is that you can't assume that anyone else will give the information.” RBN1*

‘Filling the gap’ was both for individual woman (micro) and systems (macro) benefit. A few nurses described their efforts to up-skill and inform hospital or community health staff to the issues and experiences of women with breast cancer, in an effort to improve the care provided by other healthcare professionals.

*“I don't think a general clinical nurse has time or the ability ... they don't seem to acknowledge any of the ... emotional issues, the information issues, that woman require. ... I felt that my role enabled those needs - it filled that gap, that hadn't been there in the past. I filled the gap by being able to provide the information to the women and give them some understanding, but also providing some information for the staff and to the other nurses caring for the patient in their clinical roles.” RBN2*

The nurses' descriptions portrayed that RBNs took advantage of their contact with women to identify and rectify various system's faults for individual women.

*“...again you can't assume another health professional has gone through that with them. Because the system can fail, and we're here to try and prop it up.” RBN1*

There are boundaries on the RBN care, whether organisationally imposed with employment parameters, or capacity-based. Although the boundaries of their roles generally fell in line with their skills and capacities, the RBNs did describe themselves taking liberties to ‘step beyond their brief’ when they identified an intense need or a ‘hole in the system’. RBNs described how they took on tasks outside of their position description if no other relevant services or support was available.

*“I had one young lady who was leaving her boyfriend. She had a young child, and I had to help her to become re-housed. So, I kind of feel that in a lot of ways you step beyond your brief, or what you should be doing, but at the same time feeling obliged to help regain the full picture for people. So ... you are sometimes seen as the point of call for everything.” RBN1*

Employing organisations were portrayed as allowing RBNs to broaden their support to those not formally within their system, in an effort to support certain individuals who clearly needed more support. A few nurses described their management supporting them to provide some RBN time to women not formally cared for from within their organisations.

*“She wasn’t actually one of our patients... [my manager said] ‘it’s OK we’ll give you a few hours to just sit and to listen to her and to direct her on a few issues’... ” RBN2*

RBNs described “propping up the system” when they found mistakes made by others, or individuals who “fell between the cracks”.

*“The last time I rang one of them (i.e. a surgeon) was to say, ‘Do you want me to take these sutures out of this lady, because, you know, you didn’t do it last night when she came to see you.’ ” RBN4*

One nurse described coming into contact with a woman who had ‘slipped through the cracks’ of the system, and had somehow managed to be on a reconstruction waiting list for three years with a specialist who was no longer practicing. One RBN utilised her contacts to raise awareness of the woman’s situation, and her reconstruction was scheduled soon thereafter.

#### **7.1.8. Advocating**

Advocacy care processes were commonly named up by RBNs. They described advocating on client(s) behalf, and/or supporting them to act on their own behalf.

Advocacy was undertaken on micro and macro levels. The RBNs suggested the implementation of their roles was a significant step towards acknowledging the importance of psychosocial needs. Furthermore, RBNs advocacy work assisted in supportive care principles and RBN roles gaining acceptance from nursing and medical professions.

Nurses reported how an extra phone call from them could assist women to gain access to services.

*"There were women that really struggled with lymphoedema, and so a referral to the physiotherapy into the (local hospital), that was a bit problematic at times, but if I'd just ring, I'd be able to get them in..."*

*RBN5*

RBNs described their need to balance advocating for women and maintaining professional respect with health provider colleagues. This was expressed as important to maintaining the ongoing support and acceptance of the role - and individual RBNs - from key clinicians. At times RBN's actions had the potential to cause conflict between a specialist and herself by fulfilling the supportive care requested from the client. One nurse described 'treading a fine line' of competing demands in an attempt to achieve the best outcomes for her clients whilst 'maintaining the peace' with key clinicians.

*"It's a fine line between advocating for the women and not [PAUSE] putting the treating specialists offside, I suppose."* RBN5

*"We are advocates for our ladies, but we also want to ... work alongside quite professionally with our colleagues. So something I find difficult is, to ... make women feel empowered to question health professionals, because it is their body, it is their life and if they don't feel comfortable with ... Those health professionals know where a lot of the information's coming from, so when these women go to their appointments and they question, or say they do or do not want*

*something – [I] try and find a balance between ... - empowering the women and not falling out with other colleagues.” RBN1*

One incidence of macro advocacy care processes was when RBNs worked with other stakeholders to improve the availability of prosthesis and the means through which they were provided. This task was a collaborative advocacy effort.

Yet in other instances RBNs deemed the advocacy role out of their realm of control. This happened when a nurse identified a problem within the system, but perceived she lacked the ability to improve the situation. One instance of this was when a nurse commented on the lack of a multidisciplinary team, and pointed to the need for a specialist to make the push for its existence. Another example of advocacy issues being beyond nurse’s perceived control was the reporting of laboratory results.

*“I found it a bit conflicting and I was sort of always asking ‘why does this poor woman have to wait three weeks when this other one is able to get her answer in a week?’ But then that was something that was completely, completely out of my control.” RBN2*

#### **7.1.9. Client Finding**

RBNs described attempting to set up procedures and protocols to enable women to be referred to their RBN services. Yet, it was clear by their descriptions that many potential clients were not referred, and thus RBNs were actively involved in client finding. Client finding, or identifying eligible women to offer their services, was a common theme amongst some RBN services (i.e. Community and Private Hospital) where regular referrals were often not in place. This is a systems level or macro intervention. RBNs described locating eligible individuals from inpatient hospital lists or pre-assessment wards. In the case of the RBNs, they described case finding as a means of identifying cases to be referred to them, or more correctly, to offer their breast nursing services.

*“I’d print off the bed lists for the upcoming week, and so ... such and such coming in for local incision CA breast, I would give them a call and introduce the concept of who I was...” RBN5*

This is an important departure from the previously described breast nursing practices. Client finding may be more common in rural or small population areas, and likely more common for newer RBN positions in locations where the presence of a BN has not been the norm.

#### **7.1.10. Collaborating**

Nurses described collaborating with individual providers to support women in their journey with breast cancer. These micro and macro interventions were undertaken for individuals, and for system enhancements. Many different collaborations were described by RBNs<sup>53</sup>.

Specifically, nurses often described working in collaborations to support high needs patients. These collaborations were at times with other RBNs, and even more frequently described as with other supportive services.

*“I’ve got a pretty good relationship with the social worker in (treatment ward) and I ring her a lot, and I bounce things off her and get her to follow-up people when they’re coming in for treatment into (treatment ward) ... I’ve had a chat to the social worker and we’re going to prop her up between the pair of us. So I’ve got her, every Friday, I know she’s coming in at half past one. So then I’ve said to the social worker who’s going to be there to, so I’ve said ‘I’ll catch her this Friday,’ ‘ (RBN4), see what’s happening for her, et cetera’ I said, ‘Well, could you give me a ring and feedback next week?’ “ RBN4*

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<sup>53</sup> The capacity to collaborate is also discussed in the Socio-Cultural Features section on page 247.

One nurse's use of the collective plural subject, namely 'we', when discussing difficult cases made it clear the nurse and others were working collaboratively, despite the lack of a formal multidisciplinary presence. For example, when discussing a high needs client, she commented:

*"Whether she was clinically depressed, we talked about it, we didn't think so..." RBN5*

All RBNs preferred the idea of being able to care for women within a multidisciplinary team who regularly met to discuss cases, enabling all team members to have a broader, more holistic view of clients, but many saw this as unlikely for their regional healthcare environments. As such, they expressed doing the best they could within the present setting: *"it's a matter of trying to work the best that you can"* (RBN3).

RBNs described accessing information resources from other organisations in an effort to ensure appropriate information was available for women, and RBN described their efforts to assist in stocking specialists' offices with appropriate booklets for timed distribution.

On the macro or systems level, RBNs described collaborating for a common purpose to improve systems of care, or the experiences of women with breast cancer generally. These alliances, both formal and informal, helped to solve problems and enhance leadership. The RBNs described their participation in a state-wide 'Breast Nurse Network' as a means of support and learning from one another. Furthermore, an informal regional RBN alliance was made between nursing working across two non-linked *Private Hospital Sites* to ensure women were supported when either nurse was away on leave or unavailable.

#### **7.1.11. Peer Support**

RBNs described supporting with one another in a number of formal and informal ways. Formally, the nurses formed a state-wide network of RBNs called the Breast

Nurse Network. The professional and personal support provided by colleagues before, during, and after regular gatherings was consistently earmarked by RBNs as having a positive effect on their ability to provide quality care.

*“...what was a great help was having the Breast Care Nurse Network, that really was helpful, a great support. ... I thought that was probably one of the most supportive things, our regular get-togethers, and also just to know that there were, other nurses around to network with. ... That wasn't only on a professional level, that was also on a personal level as well.” RBN2*

*“Certainly I've found it enormously beneficial with our Tasmanian Breast Nurse Network ... it's been absolutely fantastic for me to be able to have contact with the others ... getting there and having some nice time chatting ... and whinging about things that have happened, ... so off-loading and sharing that in a very confidential environment, ... being able to ... debrief with each other and then having some sort of education has been really great.” RBN3*

Informally, RBNs benefited each other with a much needed source of mentoring and supervision which RBNs identified was lacking within all employing organisations.

*“But what was important, I think, was to have a mentor or someone to talk through to make sure that you were on the right track in terms of supporting the women. I think that supervision-type role, although I didn't have anyone formally set up, that's where I used other breast care nurses to say, ‘Look, I've got this really difficult situation.’ ” RBN5*

Furthermore, RBNs went on to support the establishment within another region of a *Community RBN*. This new RBN described relying on the experiences and insights of the RBNs to develop her service.



In summary, the RBN role contained micro and macro processes of care. Nurses reported undertaking care in a client-centred, accessible, open, and empowering manner, whilst utilising high level interpersonal and assessing skills throughout. RBN processes of care consisted of undertaking holistic assessments, providing a pivot point, linking, being an information provider and ‘translator’, dealing with emotions and coping, supporting decision-making, assessing, ‘filling a gap’, advocacy, client finding, collaborating, and peer support. Furthermore, RBNs conveyed they were most effective at these interventions when they ‘sat at the interface’ and were able to communicate with providers and services across organisational divides, and access women regardless of the site.

## **7.2. Influence of Rural Breast Nurse Characteristics on Practices and Outcomes**

This section describes how RBNs’ perceived their personal and professional characteristics might influence nursing practices and client outcomes. Given the potential breadth and depth of RBN involvement in a woman’s journey with breast cancer, the nurse (i.e. intervener) has the capacity to impact psychosocial outcomes. “The intervener is involved in the different activities constituting the intervention and in a dynamic interaction with the participants during the sessions” (Sidani & Braden, 1998, p.89). Together with the client, and framed in the context, RBNs professional and personal characteristics shape the intervention provided.

RBNs identified how their own characteristics influences women’s supportive care needs being met, and the care provided to them. Interveners “are individuals who differ from each other on various characteristics and thus cannot be assumed to be equal in who they are, what they know, what they do, and how they do things” (Sidani & Braden, 1998, p.88). Thus the ‘RBN intervention’ varies across individual RBN services.

### 7.2.1. Professional Features Influencing Practices and Outcomes

This section details the professional features which RBNs expressed could influence nursing practices and outcomes received. “Professional characteristics include the skills needed for properly carrying out the activities making up the intervention” (Sidani & Braden, 1998, p.88). The professional characteristics described by RBNs are expertise and experience, and professional relationships. The professional characteristics RBNs identified as affecting outcomes and care provided can be grouped by ‘what they know’ and ‘who they know’.

The ‘what’ knowledge contained their level of competence or expertise in the clinical areas pertinent to the RBN care (namely surgery, radiation and chemotherapy, home care, and psychosocial support), as well as knowledge and experience with health systems and healthcare sites. The ‘who they know’ was related to the RBN’s relationships with key healthcare players (e.g. gatekeepers) in order to obtain information or access to clients.

The experience and expertise of RBNs were strongly linked with their comfort, confidence, and activities undertaken. When RBNs had previous professional experience in aspects of the RBN role, they described greater confidence in their understandings of the processes involved, and their ability to assist clients with related issues. When RBNs had utilised similar interventions in a previous professional role, including intervention skills and principles, this enhanced their ability to confidently contribute to a woman’s journey. For example, nurses identified the overlap in skills and principles in working with emotional and body image issues with previous roles.

*“Working in stomal therapy, a lot of the concepts were very similar, and especially in terms of changes in body image and the emotional issues that go hand in hand with the diagnosis of cancer, the support and advice that people need when they're first diagnosed, and as they progress with their treatments.” RBN6*

One nurse mentioned the benefits of having an understanding of the clinical practicalities of wounds.

*“I think that my confidence came from the fact that I’ve always been a clinical nurse so I’m used to dealing with that side of things. So the processes, wounds, experiences, and needs for that were fairly obvious.” RBN2*

Previous experience in the oncology area was heralded as very beneficial by all RBNs.

RBNs also described adapting their role to fit their limited relevant clinical knowledge and experience in breast cancer specific healthcare pathways.

*“...My background knowledge in the science behind [breast cancer and it’s treatment] was probably fairly minimal. I think that probably encouraged me to direct women rather than giving them direct information. ... I didn’t have the confidence and knowledge background so much, in oncology per se, like a nurse that had been in oncology...” RBN2*

Experience and knowledge with health and supportive care systems and healthcare sites improved RBNs knowledge of the processes involved and their capacity to support women in their journey. Knowledge of available support services, and relevant criteria, increased RBNs’ ability to suitably refer clients for further support. For example, when RBNs were used to working with staff within other sectors in a similar way, then transitioning to RBN work seemed a simple step to make for both RBN and site staff.

*“(The RBN role) complemented the liaison position that I do as well, because I can already move through the public and the private sector hospitals and I’ve already established a network, say through the*

*(cancer treatment site) and the discharge planners in the private sector.” RBN4*

The relationships, or professional links and connections, that nurses had developed in previous roles improved their capacity to support women. These links and connections meant an RBN knew the key players, and were known by them. Positive relationships, particularly with ‘gatekeepers’, appeared to increase the freedom allowed to RBNs to access patient lists and healthcare sites, which another nurse unknown to key players may not have been able to access. This increased freedom and access to information appear to have had particular benefit in hospitals around pre- and post-surgery timeframes. RBNs described themselves gaining access to surgical lists to identify patients to make contact when referrals had not been received from elsewhere.

*“...that was only because, you know, we’ve got this fabulous connection with the hospital we’re in and out of there and (RBN name)’s the same. ... She’s got all those contacts with (the chemotherapy ward). She knows who’s who, where to go and all that interaction is just fantastic...” RBN6*

### **7.2.2. Personal Features Influencing Practices and Outcomes**

This section details RBNs’ personal features which may influence nursing practices and client outcomes. The RBNs identified their own personal characteristics as influencing their ability to meet the supportive care needs of women with breast cancer, and the care RBNs offered to them. “Personal characteristics include attributes related to demographics, personality traits, and interpersonal style” (Sidani & Braden, 1998, p.88). The RBN’s personal characteristics identified as affecting nursing practices and outcomes include comfort and confidence in their skills, with client groups, and challenging issues, their relative age, and emotional awareness.

It is important to note that the analysis clearly demonstrated one RBN in particular lacked confidence on many levels, including her own skills, knowledge, and personal comfort with emotions. This nurses' open expression of her lack of confidence and comfort and its effect on the interventions she provided assisted the researcher's understanding of how important this trait can be, although often taken for granted. While this RBN highlighted the many effects of personal comfort and confidence, the themes were reiterated by other RBNs, yet the effects of confidence were expressed more commonly in a positive light by other RBNs.

The analysis revealed RBNs organised their role around those areas which they felt the greatest comfort and confidence in their skills. For example, if they felt most comfortable around practical support, then this was of major focus of their RBN care.

*"I put on my hat straight away as a community nurse..." RBN4*

Conversely, if the RBN lacked confidence in this area, then this part of RBN care was understated. One nurse insightfully questioned herself whether the RBN interventions she most often provided were those most needed by women, or the ones she portrayed to be available through her role.

*"Is that because of the way I played the role, but this is where they sought their support from me rather than this. And it probably is because that is the role I played, yeah... or is it because of people's understanding of the nurse ... as a caring, ... hands on ... person. Is that what ... the majority of peoples' thoughts are? " RBN2*

When RBNs felt comfortable with challenging issues within themselves, they displayed comfort in addressing these issues with women. The RBNs identified the importance of comfort with their own emotions, sexuality, and death as key to being able to provide support for women dealing with these sensitive issues. Clearly if RBNs were comfortable with these issues themselves, it is much easier to

convey an openness to discuss these challenging and delicate topics with their clients.

*"I have trouble coping with my own emotions sometimes let alone anybody else's. ... I did have a realisation that these issues were, for the majority of women quite a large issue." RBN2*

Another nurse was clearly comfortable in her discussions with clients around sexuality:

*"...you've got to ask people that sort of question about how they're feeling, you know, in themselves. Have they been able to resume their normal sexual activity, you know, do they feel comfortable with their husbands touching them, how do they feel themselves about their body image." RBN6*

One nurse described how her own skills and comfort improved as she gained greater experience in talking to women about sexuality.

*"...I became more comfortable as I went through and developed my own skills. I got more and more comfortable, and I was able to talk about it, it was quite good." RBN5*

Nurses' comfort with sensitive issues impacted on how they went about providing care. For example, when dealing with sexuality specifically, RBNs took different approaches to how overtly the sensitive topic was raised, or if it was raised at all.

*"I didn't sort of dare say let's talk about this issue, it would just come up through conversation." RBN2*

Another RBN described non-threatening ways of bringing up sexuality in discussion.

*" 'Is everything okay, now that you're home, now that you wear your own clothes again, you know, back in your own bed, you know, what's*

*happening? Is everything all right between the two of you?', and then you might get it." RBN4*

When the nurse was able to make the woman feel comfortable through a positive nurse-client relationship, beneficial processes of care resulted.

*"I usually find that they're ringing me with questions once they feel comfortable with me." RBN1*

Due to the emotionally connected and intimate nature of the nurse-patient relationships, and the ongoing support provided, the RBNs conveyed that sexuality issues often ended up being discussed, whether brought up specifically by the RBN or not.

One RBN noted her relative age as having an impact on the comfort level of her clients. She felt some clients and/or their partners felt inhibited in her presence, even though she felt she had the confidence, knowledge and skills to be of assistance. Thus, her clients' presumed discomfort with her younger age affected the RBNs ability to support certain women and/or couples.

*"... I'm a lot younger than a lot of the clients that I see, so I do find that difficult too, sitting between a man and a woman who might be 30 years older than me, they find it - well, not so much the women - but the men sometimes find ... it a little bit de-moralising..." RBN1*

A few RBNs stated their awareness that although they knew a lot about the systems, steps, and experiences of women with breast cancer, they had never truly been in the woman's situation.

*"I tell every woman that, 'I haven't had breast cancer. This is what I can do for you. This is what I can offer.', but I don't truly understand what the experience is like." RBN3*

In summary, RBN's personal and professional characteristics influenced the care provided, and the outcomes for women. RBN's professional experiences in the primary clinical areas of breast nursing impacted their knowledge, expertise, and confidence. Positive experiences also led to professional relationships with key players in the healthcare system which increased their access to sites and clients. Thus, nurse's professional characteristics impacted their relationships with women and other health professionals, as well as their comfort, confidence, inclinations, and preferences to pursue different interventions.

RBN's personal characteristics influenced the nurse-client relationship, the care provided, and the outcomes for women. The influential personal characteristics included RBN's comfort and confidence in their skills, with client groups, and challenging issues, and their relative age, and emotional awareness. These characteristics were described as affecting how RBNs presented their role and went about providing care, and ultimately the intervention received by clients. These findings portray how nursing practices and outcomes for women are influenced by the personal and professional characteristics of the RBN.

### **7.3. Chapter Summary**

In summary, this chapter presented a qualitative description of the nursing practices of RBNs, and the influences of these practices on outcomes. Additionally, the findings demonstrated that RBN professional and personal characteristics also have the potential to influence rural breast nursing practices and clients' outcomes. The next chapter continues to present the qualitative findings related to influences on nursing practices and outcomes.



## **Chapter Eight: Rural Breast Nursing Practice – Nurses’ Insights on Client and Contextual Influences**

Following on from the previous chapter, this chapter continues to present the qualitative findings of RBNs’ perceptions of the influences on nursing practices and client outcomes. As with the previous chapter, this chapter continues to address the sub-question: *How do RBNs describe their practice, and what factors influence their practice?*

Findings are reported in two sections. The first section presents women’s influence on nursing practices and client outcomes, namely her personal, health, and resource factors. Additionally, this section highlights the presumed inevitability of certain emotions and experiences for women with breast cancer. The second section describes the physical and socio-cultural contextual characteristics that influence nursing practices and client outcomes.

### **8.1. Influence of Client Characteristics on Practices and Outcomes**

This section details RBNs’ perceptions of the clients’ influence on RBN care and client outcomes. RBNs regularly described how client characteristics affected their outcomes, and the care RBNs provided. Nurses portrayed the influence of women’s characteristics on their supportive care needs, and unmet needs profiles. The characteristics were seen to impact positively or negatively on a woman’s journey, as well as on the nurse’s and healthcare team’s capacity to assist with women’s supportive care needs. Women’s characteristics were categorised as personal factors, resource circumstances, and the health / disease profile each woman brought to their experience with breast cancer.

### 8.1.1. Personal Factors

This section portrays the personal characteristics of women that RBNs perceived influenced care and outcomes. These characteristics were related to a woman's outlook on life, 'who she is', her beliefs and values, treatment preferences, and participation in health decisions.

RBNs found some women more challenging to work with, or provide health teaching to, simply because of 'who they were'. This is recognised by the researcher as a combination of the interaction between client and RBN characteristics.

*"There are some women that just are harder to talk to and explain things to and it really - often does come down to the clients." RBN1*

RBNs portrayed woman bringing their outlook on life to the experience of breast cancer, just as they do to other aspects of life. A woman's approach to life was described to significantly improve or worsen the woman's breast cancer journey. The RBNs recognised they had little impact, if any, to the woman's approach to life. RBNs commented on women bringing their approach to life and/or personality style to their breast cancer experience.

*"She was always ... negative in terms of the future, her disease, the 'why me?' type stuff, and that became difficult ... that then turned into lack of motivation ... to make any decisions. ...We just wondered whether or not that's the way she managed her life." RBN5*

*"I can't go about changing personalities, and I think you must acknowledge that there's only so much you can do. You meet somebody and you think, they've always been a bit highly stressed. And so you can't change somebody ... who they are, is who they are..." RBN4*

Yet for a select few women, it appears the cancer experience did change 'who they were', resulting in their embracing and surmounting major personal challenges. RBNs described cases where women overcame personality styles or life situations which had limited their life experiences before breast cancer (e.g. leaving an abusive husband). The cancer experience was seen as catalyst for these life changes.

*"...she's now out and doing things in the community, getting involved in the community, and helping, volunteering for things and that sort of thing. Whereas she was just a stay at home shy little lady. ... you hear of women say that breast cancer has changed their lives and she is one of these women that happened to." RBN2*

*" 'If he won't stand by me now, what if I get really sick?' ... She said, 'I'm going to leave him.' " RBN6*

The beliefs and values of each woman impacted how she related to herself, her support network, and to the healthcare professionals in her journey. For example, RBNs illustrated how a woman's openness, or willingness to discuss potentially sensitive issues, influenced what was and was not discussed in their consultations. Again sexuality was highlighted as challenging to discuss with certain private clients.

*"I guess it also comes down to the client as well. ... If they don't want to - if they are a very private person. So you do have to respect that as well." RBN1*

*"Right up front when you start asking the practical questions you get a bit of a feel for how the women are going to react when you get down to ... these more sensitive issues." RBN6*

The treatment preferences of a woman clearly impact her breast cancer experience, and the support services she received. The nurses described how some women

elected to forgo recommended treatments or services, including breast care nursing. Nurses expressed support of a woman's right to choose which support services she needed and or wanted.

*"... There were women that chose not to see me. They had every right." RBN5*

*"... The Breast Cancer Support Service ... the majority of women don't seem to want to access it anymore. ... So they declined the offer ..."*  
RBN3

A woman's involvement in health decisions impacted her needs, and the support needed by RBNs. Clients seeking greater participation in health decisions wanted to know treatment options, treatment locations, and occasionally even which specialists might be best for them. RBNs described assisting women with their decision making, yet leaving the decisions to the woman.

RBNs reported consistently putting women and their needs at the centre of their care processes, and asking them to participate in driving this process (as described in Chapter Seven). Yet, the choice to participate was client's alone.

*"I can't read people's minds. I don't know what they need, unless they tell me..." RBN3*

Women's preconceptions were noted as having limited their realisation of the choices available to them, often leaving decisions up to specialists instead.

*"A lot of the times women didn't feel they had any choice. They thought that choice was already made for them. They thought that was taken away, because there's still that concept of the doctor's always right, and I better do what the doctor says." RBN5*

Additionally, the dynamic between a woman and her RBN might not have been a good fit.

*“...some people would say, they might not have gotten on well with me, whereas they might have gotten on well with somebody else...”*

*RBN6*

### **8.1.2. Health Factors**

This section portrays the health characteristics of women with breast cancer that RBNs perceived as influencing nursing practices and client outcomes. A woman's health, disease and treatment profiles were identified by RBNs as affecting her journey with breast cancer, the RBN care offered, and her psychosocial outcomes. One RBN summed it up this way:

*“I would class as more needy - those who have complicated lives, and also complicated treatment plans, that their disease may be more advanced, they're going to require more reviews than most.” RBN1*

Each individual woman's health profile affected her breast cancer experience. A client's functional status, specifically her physical and psychosocial functioning, impacted her psychosocial outcomes, and the RBN care provided. One nurse detailed how a woman's large breasts made the post-surgical period more uncomfortable, and how the RBN assisted her to find a practical solution to her discomfort. A woman's underlying health and/or illness status was described as complicating or exacerbating her breast cancer journey. For example, co-morbidities were described as complicating a woman's recovery.

A woman's disease profile affected her cancer experience. The cancer illness severity and staging affected the issues women faced, and ways in which they were supported by RBNs. An uncommon cancer disease type with a complicated or uncertain disease trajectory was clearly more challenging than a 'straight forward' or typical breast cancer case. The cancer mental health burden was noted to be of particular significance. Nurses portrayed the cancer diagnosis as inevitably stressful and uncertain for women, who face real concerns about their own mortality.

RBNs illuminated inevitable emotions and experiences for women with breast cancer during their journey. They detailed the inevitability of certain negative feelings and experiences for women, and described emotions as challenging, but part of the unavoidable reality of most cancer journeys. Indeed, emotional support is complex. RBNs explained that while the negative consequences from these inevitable elements of the cancer experience can be alleviated by forewarning and support, they cannot be taken away or erased completely.

*"... You can't allay people's uncertainty about the future. You can't. What can you say to somebody? ... I can't say to them, 'You're going to be okay.' Because they might not. " RBN3*

Certain emotions were conceived as a 'justifiable reality' for these women, i.e. these feelings were real and understandable given the circumstances. RBNs named the initial shock, sadness, and reoccurrence fears as unavoidable feelings.

*"...All women will be upset. They're bound to be." RBN3*

*"[Fear of recurrence] is a shocker, for all of them I suppose. An analogy that one young woman used is: 'Cancer is always with me and it's my friend. It's always walking beside me, even though I know it's not in my body it's walking beside me because at any given time it could come back, and that's true.' " RBN5*

The treatments undertaken by women influenced their needs as well. For example, women who underwent radiotherapy had tender skin or a burn to heal, whereas women who underwent chemotherapy dealt with nausea. As the quote at the beginning of this section described, a complicated treatment plan led to greater needs. RBNs explained certain breast cancer treatments having inevitable impacts on everyday life, namely low energy levels influencing a woman's capacity to work and enjoy the usual activities of life.

*"... it is the most tired that they will ever feel in their entire life." RBN1*

*“Your usual routine and lifestyle will never be the same again, until you’ve worked through everything, you’ve gone through ... (treatment), and then you might get some sense of normality...” RBN6*

The perceived symptom burden varied across treatments and individuals. The symptom burden experienced by individual women shaped their needs, and the support provided by RBNs. So, for example, although RBNs typically attempted to prepare women to watch for lymphedema, only some women experienced this symptom burden. Although the symptom burden associated with treatments was to be expected, the profile and extent of the burden varied between women and treatments undertaken.

### **8.1.3. Resource Factors**

This section portrays the resource characteristics of women that RBNs perceived as influencing nursing practices and client outcomes. Client’s resources identified as shaping women’s needs profiles and RBN’s care were individual strength and resilience, level of social support, social and professional responsibilities, insurance/financial status, and their proximity to health and support services.

Women were seen as ultimately needing to draw on their own inner strength and resources during the challenging moments. A women’s personal resilience and coping strategies were seen as key factors that could buffer the negative experiences with a breast cancer journey.

*“...When they are in crisis, when they have just had their breast off and when they are about to face chemotherapy, the journey is tumultuous, they have to draw on such inner strength...” RBN5*

The availability of social support was described as beneficial to women’s ability to cope, and their personal outcomes. Social support was described most often as coming from friends and family.

Professional and social responsibilities added extra pressure for women. When women were employed outside the home and/or had caring roles with children, parents, or a partner, the RBNs identified that they had a greater need to 'be OK'. The nurses described some women not allowing themselves the time and space to recover properly from treatments. One RBN described a woman's early return to work so that she would not lose her job.

*"Which can be very difficult for some women ... especially a younger woman, she's got a family, and work, all of those sorts of issues - so it is just talking to them about that, just the logistics of it." RBN3*

*"... Because physically she was the main engine of her home and she just didn't have that energy..." RBN5*

*"It is difficult for people that have busy lifestyles that want to keep working or have to keep working, or who have children, it is very difficult." RBN6*

A woman's financial status, often operationalised as the presence of private health insurance, or the pressure to work outside the home, was seen as having an impact on the options available to her, as well as the absence/presence of financial pressure.

One's rurality, or proximity to health and support services, played an important role in what might be available to women. More rural clients were described as having more telephone versus face to face consultations. Furthermore, RBNs described greater difficulty linking in with support services for more remotely based women.

In summary, RBNs perceived that client's personal, health and resource characteristics influenced breast nursing practices and client outcomes. Nurses illustrated how a woman's personal outlook, beliefs, and preferences influenced RBN care and outcomes. Also a woman's health, disease and treatment profiles affected RBN care, i.e. her functional status, illness severity, treatments undertaken,



and symptom burden shaped her supportive care needs and the RBN care provided. RBNs also illuminated a group of what they perceived as unavoidable feelings, emotions, and cancer experiences for the women with whom they consulted. Nurses witnessed how the resources available to women, such as support networks and financial resources, and her responsibilities inside and outside of the home affected an RBN's choice of interventions and the woman's outcomes.

## **8.2. Influence of Contextual Characteristics on Practices and Outcomes**

This section conveys RBNs' perceptions of the physical and psychosocial contextual characteristics influencing RBN nursing practices and client outcomes. RBNs expressed that the setting characteristics and context in which an intervention is delivered have the potential to influence RBN care as well as client outcomes. This section reports on RBNs experiences of the contextual factors which they perceive to affect the processes of care, and their capacity to meet supportive care needs. It should be noted that meeting needs includes enabling women to meet their own needs, as well as supporting women by meeting their needs. Within the theory-driven approach, contextual factors are considered setting characteristics (Sidani & Braden, 1998).

Setting characteristics include the physical and psychosocial features where the intervention takes place. In this study, the specific site(s) of intervention delivery and the regional healthcare community were considered the setting. "Ignoring the potential influence of the setting on the outcomes expected of an intervention has serious implications for the external validity of conclusions" (Sidani & Braden, 1998, p.101). The following sections detail the physical and psychosocial features that RBNs perceived impacted care processes and outcomes.

### 8.2.1. Physical Features

The setting's physical features are those relating to the physical environment. The researcher conceived the physical features grouped by time and space, sites and services, and employment parameters, as described in the below sections.

#### 8.2.1.1. Time and Space

The contextual physical features of time and space noted by RBNs in this study included the surgical in-patient duration, pathology reporting timeframes, proximity of cancer services, and the rural reality for services and clients.

##### 8.2.1.1.1. Timing

Shortened surgical in-patient duration (i.e. quick hospital turnover) affected whether RBNs could make contact with women face-to-face before or after surgical treatment. This limited their capacity to prepare women for the upcoming procedure and/or support their recovery efforts and preparations for the next steps.

*“With the new treatments for breast cancer women are in and out of hospital so quickly, they're often only in hospital for four hours, so we don't actually get to see them. And they come off the farm or their property, they come down to (location) to have their surgery, and they're gone before we can have contact with them.” RBN1*

Pathology reporting timeframes were identified as influencing nursing practices. All RBNs made reference to delays in the availability of pathology results. Many RBNs described inconsistencies in timeframes, negatively impacting women's distress as well as specialist's capacity to gain a clear picture of her outlook and propose the next steps.

#### 8.2.1.1.2. *Rurality*

The reality of rurally based clients affected travel time, the incidence of home visits, and the use of telephone consultations. The long distances affected how care was provided, namely limiting capacity for home visits and an increased use of telephone consultations. The shortened surgical in-patient durations discussed earlier were exacerbated for more rurally based patients, who were then more likely to miss out on consulting with the RBN in person.

*“Sometimes they live a long way away and we just don't have the time to go and see them.” RBN1*

RBNs described choices as limited, if available at all, for certain treatment options in most rural regions. For example, if clients were to undertake radiotherapy treatment, RBNs described the local hospital as the only option, unless relocation for treatment was possible.

*“If you're in radiotherapy you're not going anywhere but the (local hospital).” RBN4*

The small size of rural communities led to other challenges for RBNs. One RBN described the difficulty in maintaining a professional distance from clients outside of work hours.

*“...It can get a bit clouded and fuzzy around the edges, and [the area] is very small, and people do run into you or look you up in the phone book.” RBN1*

Another nurse expressed that as they worked in a small communities, RBNs had to be even more cautious about balancing advocating for women and maintaining collegial relationships with other healthcare providers.

*“... being a small community, you had to be really careful, I thought...”  
RBN5*

Rurality also affected RBNs' experiences of the role. The nurses described issues relating to isolation including loneliness and the greater need for professional development. The reality of being a sole RBN in a rural regional area or organisation was described as follows by one RBN:

*"You get a bit lonely, the loneliness. That has been alleviated somewhat from the establishment of the Breast Nurse Network .., but I still - I feel very much alone at times, wandering around in the wilderness." RBN3*

This RBN also described how being an isolated healthcare provider increased her need for continuing professional education.

*"Going to things like the Breast Nurse Conference I found very helpful, very rewarding, ... especially because there's only me here, working in isolation ...I don't have a great 'well of knowledge' here that I can go drink out of, if you like." RBN3*

#### 8.2.1.1.3. Proximity

The RBNs described how their service's proximity to other cancer services influenced clients' accessibility to RBNs, and RBNs availability to clients and other members of the healthcare team. A *Public/Private Hospital RBN* described her ability to walk women to the chemotherapy ward from her office, and being able to 'pop over' to see clinicians. Her office was centrally located amongst other services, effectively at the same site. This allowed for clients to drop in and visit the RBN quite easily. In contrast, the *Community RBNs* were situated off-site from all other cancer services. Thus if Community RBNs wanted to make face-to-face contact with a woman, she had to book a car for travel, as well as secure access to another organisation's healthcare site. Proximity to other cancer services also provided for 'piggy backing' with other critical health appointments, assisting clients to prepare for specialist appointments and consolidate understandings afterwards.

A hospital-based RBN described her ability to show women the treatment sites, drop in to see them daily while they are in the hospital, and synchronise consultations with other providers to minimise client's trips to town. The nurse explained the ease with which she could connect with clients on site, whether dropping in to see in-patient clients, or them coming in to see the RBN as an out-patient.

*"...Especially here at [hospital], I will usually see them every day while they're in hospital post-operatively. It's a little more difficult when they're in [another hospital], just because of the tyranny of distance, but even then, I'll try and get to see them at least once." RBN3*

*"What the physiotherapist and I will try and do is to tie important stuff together. So instead of [the client] having to come in all the time, to come in to see me, then they'll go and see [physiotherapist] ... and come and see me after." RBN3*

Whereas, a *Community RBN* described her choices in linking with many clients across disperse locations:

*"... because we're limited in time. There's a lot of phone contact. A lot of the ladies don't even know what I look like. And that really comes down to how many referrals we're getting a week or a month. So I guess that is a constraint on how well we're going to service, but we can be more efficient over the phone. We can get to spread the services wider." RBN1*

#### **8.2.1.2. Sites and Services**

RBNs described physical features of the setting which related to healthcare sites and services. These features included appropriate area(s) for consultation and credible sources for referral.

#### 8.2.1.2.1. Consultation Areas

RBNs expressed the importance of private and comfortable areas for consultations with clients. Appropriate consultation areas gave clients and RBNs the space to address the full range of possible issues. Nurses reflected on the benefits of comfortable chairs, appropriately private space, ease of access, and the added luxury of windows.

When RBNs were unable to meet with women under suitable circumstances, the normal care processes were hindered. One RBN described the challenges of discussing symptoms resulting from hormonal treatment to a young woman on a mixed-gender hospital ward.

*“She wanted to know about side effects, and there was all sorts of people in that room and talking about stuff like vaginal dryness. ... I just said to her, ‘Look, there’s more to chat about, as far as this goes’, I gestured that maybe this isn’t the best place, ‘Don’t think that I don’t want to talk to you about this, but this should be a talk between us when it’s a bit - privacy is an issue in here’, and she was fine with that, and I did see her the next week.” RBN4*

Another nurse described being asked to look after a woman’s chemotherapy administration while she was with the client.

*“ ‘I’m not here to run your drug treatment program. I’m here to talk to this lady’, and I couldn’t talk to her anyway because there was just too much interference.” RBN5*

Inappropriate office consultation settings inhibited RBNs sense that they could offer their consultation services to women, as they envisioned the available consultation space was not suitable.

*“... I was sort of stuck away in a little office down that back corridor. ... I probably would have conducted um, more follow-ups and that sort of*

*thing, as am, sort of with out-patient women, if I had felt that, ... where I was situated and the office that I had to use was a bit more pleasant. ... Yeah, the environment let's say, made it difficult.” RBN2*

RBNs who travelled between healthcare sites, most notably the *Community RBNs*, were reliant on other organisations to provide appropriate consultation space. It seemed that in the majority of cases an appropriate space was unlikely and or not possible. Again, the impact was exacerbated for rural women, as contact on the ward might have been the only time client and RBN could make face-to-face contact.

#### **8.2.1.2.2. Referral Options**

RBNs' referral capacity was limited by the spectrum of referral options available to women in their region, or even within the state. The rural or low population setting was described as limiting the number and quality of referral sources for some specialist services. For example, lymphoedema and psychological services, and access to reconstructive surgeons were limited if they existed at all.

*“I did have a woman that I felt might have needed more professional counselling such as a psychologist, but I always was fearful of, when I get someone that I really feel is not coping, where do I go?” RBN2*

RBNs might then be more likely to work beyond their scope, or even skill base, when a referral option is not available.

*“If I know or I feel that I'm not coping, it's too much for me, it is out of my level of expertise, then I'll refer them on, even though we don't have many people to refer to here.” RBN3*

#### **8.2.1.3. Working Conditions**

The RBN's employment parameters set the framework within which the RBN was able to function. The form shaped the function. That is, the limits and boundaries

around each RBN role affected their nursing practices. RBNs described how their practical employment parameters impacted the processes of care they were able to offer to women. Hours of employment, the regularity of hours, and the combination of the RBN role with other roles impacted breast nursing practices.

#### 8.2.1.3.1. *Employment Hours*

Naturally, the number of hours available to undertake the RBN role influenced nursing practices. Employment hours impacted the duration of support RBNs could provide, specifically if follow-up care was provided. The nurses noted that the later stages following treatment were when fears of reoccurrence were worst, and practical and daily living issues continue or sometimes worsen. One RBN went on to explain that limited employment hours due to its 'add on' design often resulted in women not receiving the ideal follow-up, i.e. follow-up consultations were dropped when time did not allow.

*"I tried on that pathway to follow them up, that four to six weeks after ... that was difficult in terms of the breast care nurse role because it sat with another role of mine, you sometimes let that one drop off... You might not get back to that, you know what I mean? If it was a designated breast care nurse position then if I was in that role I would see that that would be a very important part of following up and not ongoing but just follow them up around that time and saying, well, 'I'm here if you need me.' "* RBN5

*"For me, I have no ability to see them further on down the track ... ."*  
RBN4

The employment hours also impacted the timeframes in which RBNs could connect with clients, with fewer hours often times necessitating clients waiting for consultations. A nurse expressed her concern that her limited hours meant she was not available when a woman might have needed her support.



*"I find it a little bit difficult in this role working part-time, two days a week, and not being there for patients when they sometimes need it the most. Job sharing - we do work well together, so there is often someone there - but I guess that's one area that I find difficult, shutting off, when you know a patient might need you..." RBN1*

All RBNs expressed they did not have the hours they would like in order to provide their ideal nursing practices. One nurse expressed the potential for the RBN job as being "absolutely fabulous" (RBN3), but that she just didn't get the hours to fulfil the role's potential. Another nurse explained how she was usually unable to contact clients within a short timeframe due to her workload.

*"I get a referral prior to them going in, but I have no capacity to make contact with them, unless it says directly, the surgeon says, '(RBN name), could you please catch up with this woman prior to surgery - issues.', or something like that. Well, I will make a concerted effort with that. Otherwise I can't." RBN4*

Another nurse described how her capacity to meet with clients face-to-face had decreased over time as her hours had not increased when the caseload had. The nurse went on to explain how her nursing practices were affected by this structural limitation.

*"I think when I first started the role I saw everyone - the first visit was face-to-face. And as the role has progressed it's got busier and the hours haven't increased. It has changed the way the role has come together." SBN1*

#### **8.2.1.3.2. Employment Parameters**

Job sharing by the *Community RBNs* was meant to allow for supporting a client in their time of need. Yet, these RBNs expressed that little client sharing happened, as each nurse had their own set of clients. The job sharing did however provide critical

coverage when RBNs were on holiday leave, and allowed for a consistent site of referral for other healthcare services.

A combined role seemed to dovetail quite efficiently for the *Public/Private Hospital RBN*. This position was a combined role of Breast Care Nurse and Stomal Therapist, and as such was able to adjust her time spent on each role as required. This experience was very different to that of an “add-on” or ad hoc role.

Add-on roles with ad hoc hours (i.e. when needed or required) presented many challenges for RBNs. The lack of structure around the role, as well as their attempts to balance with their other professional roles made the add-on or ad hoc RBN role difficult to manage. One RBN described these challenges as making the role difficult to undertake.

*“I felt that because I was trying to, managing it in an unstructured role, it was basically an unstructured thing, I found it difficult, to manage it.”*

*RBN2*

Furthermore, she described the limiting pressures of her other duties from her more substantial role within the same organisation, and the limited amount of time available to provide the role.

*“...the restrictions around the time that I was available for the women themselves, trying to fit it in with my other roles.”* *RBN2*

Another RBN described the difficulty in balancing the need for administrative regularity, yet wanting to maintain flexibility for women. These challenging elements were compounded when compiled with trying to combine the RBN role with an already established role within the organisation.

*“...It was a struggle having it as an additional role. I ended up having to develop specific days that I attributed to the breast care nurse role, and that worked all right from an administrative ... and telephone point*

*of view, but I wanted that flexibility as well for women. I needed that flexibility to be able to visit the women post-operatively, or if they ... just wanted to touch base. ... It was the fact that it fitted into something else that was difficult.” RBN5*

Realistically, whatever a nurse’s employment hours or conditions were, she realised she would not always be there for a woman when she might need her.

*“Always in the back of your mind is that you're not there all the time on call, so you have to deal with these things before they become a problem and you're not there to help them with it.” RBN1*

#### **8.2.1.3.3. Client Base**

The RBNs employment parameters were broadly influenced by the number of women with breast cancer that were likely to use the RBN services. If the number of clients filtering through the employing organisation was low, the RBN was aware that the overhead was relatively high (e.g. resources put into RBN being available) for the output received (e.g. actual women supported). One RBN described her understanding that a low number of possible clients led to her ad hoc employment parameters being instituted.

*“I was trying to justify a fair amount of support for a few number of people. ... Whereas if you’ve got a bigger sort of base to work with ... you can say ‘I’ll need so many hours a week’ ... it’s much easier to structure. And there wasn’t a large base of women to work with, so the role couldn’t be sort of scheduled for a certain days of the week or certain hours and that sort of thing. So it was very much ad hoc ... on a needs basis. When there was a patient referral, I had to fit it in there with my other roles.” RBN2*

The number of women with breast cancer referred at any one time also influenced breast nursing practices. In this example, the RBN described being flooded with referrals and simply doing the best she could do to prioritise her caseload.

*“Last week I had eight referrals ... and no physical way that I could actually get to see them. So ... I was ringing these ladies just to touch base with them. ... A bit of triage on the phone as to who I needed to speak to and who I needed to see. ... Maybe not the optimum, but all I could offer.” RBN4*

In conclusion, the physical features of time and space, sites and services, and employment parameters shape the care provided through access or convenience of the RBN to the women, the physical layout, including privacy and comfort and/or general ambiance. The influential time and space characteristics identified within settings were the surgical in-patient duration, pathology reporting timeframes, the rural reality, and the RBN services proximity to other cancer care services. The findings show the physical characteristics of the setting's sites and services influence RBN nursing practices and outcomes, specifically available and appropriate consultation areas, and the capacity to refer to specialist services, impacted the care provided by RBNs, and the outcomes for women. The findings also demonstrate the practical working conditions of the RBN influence the interventions provided. RBNs identified employment hours, formal job sharing, regularity of hours, combined roles, and the number of women with breast cancer coming through an organisation as influencing the nursing practices. Not only do the setting's physical features affect the intervention and the outcomes, but so do the setting's psychosocial features.

### **8.2.2. Socio-Cultural Features**

This section describes the socio-cultural features of the setting which RBNs perceived as influencing nursing practices and client outcomes. These setting features relate to social and political factors. The contextual socio-cultural factors

described by RBNs as impacting nursing practices and outcomes were grouped by people and services, and the employing organisation, and are described in the following sections.

### **8.2.2.1. People and Services**

RBNs described the socio-cultural setting features of people and services impacting the provision of care. Broadly speaking, acceptance and support, norms, and collaborations were the prime socio-cultural contextual features identified. These setting influences came from individual, sites and services, and inter-organisational levels.

#### *8.2.2.1.1. Acceptance and Connections*

The acceptance from and support of key specialists and services of the RBN role, and the RBN specifically, was described of critical importance. The acceptance and support of the RBN role was demonstrated by earlier referrals to RBN services. Early referrals demonstrated clinicians trust in the RBN to improve the women's breast cancer journey. As most of the RBN roles were initiated not long before the study period, RBNs reported changes in the referral timing linked with greater acceptance of the RBN role, and trust in the RBN.

*"... I do think that we are seeing more ladies earlier in their journey than we did initially, and that is through acceptance of the role and being treated as part of the team - and being respected; that we're not going to actually say inappropriate things." RBN1*

One nurse described how increased acceptance from the multidisciplinary team members improved her own confidence in the RBN role.

*"...we became part of their head space ... that made me start to feel much more confident in the role..." RBN5*

The acceptance demonstrated through early referrals influenced nursing practices. The referral timing affected what could be addressed by the RBN. For example, if women were not referred until after their surgery, then the RBN was unable to support them through the initial shock, decisions about surgical treatment, and preparing for surgery. Whereas if the RBN and woman were able to make contact soon after diagnosis, the RBN could assist the woman to navigate her feelings, choices, and the healthcare system.

A specialist's demonstration of support of the RBN role positively shaped the credibility of the RBN in the client's eyes, and the resulting nurse-client dynamic. Nurses described the benefits of the support of a key clinician, often the surgeon, introducing the RBN role and providing early referrals. The RBNs believed that women approached the RBN service with greater comfort and confidence when the specialist had indicated their support of the role.

*"...by a surgeon referring it's showing the lady that they have a confidence in what we can do and the information we can provide. And because primarily the surgeon, being their first point of contact, is going to be their rock really, so by someone that these women are totally reliant on showing support for what we do, women feel so much more confident in you, mmm." RBN1*

One RBN described how early referrals led to better outcomes for women:

*"...There's a big element of panic when it comes to breast cancer, and if we can get on top of that quickly and bring that element of panic down it often stops it snow-balling." RBN1*

Acceptance and credibility from the broader healthcare team influenced one RBN's confidence in participating as a member of the informal breast care team, and furthermore shaping her nursing practices.

*“...I felt comfortable with most of them to be able to ring up and say, ‘Look I really don’t understand why you recommended this.’ But that took awhile. You had to have credibility within the multidisciplinary teams as a breast care nurse before you could start doing that, and that probably didn’t come for a little while.” RBN5*

The acceptance of the RBN role was also demonstrated on a broader level by the freedom of movement the RBN had within other organisation’s healthcare sites. When RBNs were able to move freely across public and private, and hospital and community services, they felt accepted and supported to provide appropriate care. In this study, *Community RBNs* described the greatest freedoms of movement through healthcare systems and sites: *“So I think there are a lot of positives with where we’re based”* (RBN1).

The acceptance of the RBN role by the wider healthcare community and resulting freedom of movement across healthcare sites was deemed such an important factor affecting nursing practices that *Private Hospital RBNs* recommended a community role over their present role. They perceived RBNs in the public domain had an easier time accessing clients across public and private sites, and furthermore, that *Community RBNs* were better able to provide care across the full intervention timeframe.

*“... it just became apparent that that’s where it needed to sit. ... It just works so much better in the long term for women.” RBN5*

*“... I hope that one of these ... we’ll have the same system in (this area) as what they’ve got in the (Community RBN area).” RBN2*

Moreover, an RBN’s personal and professional connections had the potential to improve the acceptance and support of the RBN role, and increase her freedom of movement and access to information and support. Positive personal and/or professional relationships made RBN movements easier. It was suggested that positive working relationships are particularly important in rural areas, where ‘who

you know' may open doors that would not normally be open based on formal protocols. One RBN described other RBNs having challenges with an organisation that played a big part in breast cancer care where she did not. She surmised that her positive RBN interactions with this organisation came from her previous personal and/or professional relationships with individuals within that organisation.

*"I felt that I worked, fairly well with them, I was able to get the information and support from them. Whether that came because people that work in there I had known personally for an amount of time. So it made it easier - as happens in a small community. ... I probably wasn't seen as 'that breast care nurse'. I was seen as 'oh yeah [RBN name], yeah'. RBN2*

#### 8.2.2.1.2. Divisions and Disputes

In contrast to the positive influences of acceptance and support, divisions and disputes negatively influenced nursing practices. Private clients were envisioned to be cut off from the support services available to public clients, thereby limiting an RBN's referral options. Furthermore, conflict and tensions between public and private healthcare services were evident in RBNs' descriptions.

*"... I was coming from within the private system and there's always a bit of antagonism between the public and the private." RBN2*

Another RBN put it this way:

*"... sometimes the health system is just so hard ... one of the biggest difficulties to support women in the private sector is stepping into that public arena, that was one of the biggest things you see." RBN5*

And:

*"I have to say in my experience of having the breast care nurse role sit in the private sector, I'm known in this community, I did my training*



*here and still I had hurdles that I still couldn't get over around the concept."* RBN5

The tensions between public and private health systems were only described as being experienced by the RBNs working from within private hospitals in their attempts to work with the public system. All *Private Hospital RBNs* depicted how their private hospital role was "received much differently" (RBN5) than the *Community RBNs* role by nursing and administrative staff.

*"She hasn't had that same difficulty because she was known in a different role, with a different hat through the public system."* RBN5

Nurses described carefully navigating these divisions whilst doing their best to ensure women's needs were met. One RBN described her fear of, and or others impressions of, crossing boundaries or 'stepping on toes'.

*"So by providing women with information on radiotherapy and that sort of thing, I may have been intruding on their role."* RBN2

Another nurse found by fulfilling an elderly single client's request to attend her first oncologist's appointment, the RBN's actions had made the oncologist "furious".

*"... (The oncologist) thought that I'd overstepped the boundaries."*  
RBN5

#### 8.2.2.1.3. *Established Routines*

Normal routines of organisations and services were described by RBNs as having the potential to either positively or negatively influence nursing practices. The usual steps or routines of individual healthcare providers could be inclusive or exclusive of RBN services. In some instances the normal routines had beneficial effects on nursing practices. For example, one surgeon automatically referred clients to the RBN service at their first contact.

*“Our surgeon had great faith in the breast care nurses, in our ability to assist with, particularly the initial shock of their diagnosis, and would send them directly from her rooms to the breast care nurse – to myself.” RBN5*

Whereas in other instances, established routines undermined RBNs attempts to provide care across all RBN treatment phases. This is illustrated by one RBN’s perception that clients were rushed through to surgery, for no apparent clinical reason, rather being given the time to absorb the diagnosis, make thoughtful treatment choices, and prepare for treatment preferably with the support of the RBN.

*“I’d prefer to see them before they came into hospital, but that sometimes wasn’t, [PAUSE] a possibility, because the - and I’m not really sure why, but the urgency of having to get them into hospital for surgery, they might be seen by the surgeon on one day and two days later they’re on the theatre list, and I could never really understand why there couldn’t be some time...” RBN5*

#### **8.2.2.1.4. Collaborations**

Collaborations extended beyond acceptance to working together productively towards shared aims. RBNs described collaborations as having the potential to positively influence nursing practices. Collaborations discussed ranged from inclusive multidisciplinary teams, to collaborations with support services generally, and RBNs specifically. Although multidisciplinary team members were described as challenging in some instances, they were also presented by RBNs as supportive.

*“I know I said it was difficult to work in a multidisciplinary team, but as the role became more a part of that team, the multidisciplinary team is your support as well...” RBN5*

The absence of certain collaborations was perceived as a missed opportunity to improve care, and even negatively impacting women's experiences. For example, one RBN explained that the absence of a multidisciplinary team meant healthcare providers had a partial picture of the woman, the proposed treatment choices offered were not informed by all specialties, and importantly, women were confused by the discordant messages given by different specialists.

*"...and I can see why women were at times confused when there was conflicting advice from their treating physicians..." RBN5*

Conversely, when collaborations were in place, healthcare providers and women benefited, and nursing practices improved. Two notable exemplars of collaborations were between regional support services and the formal and informal network of RBNs. One RBN described how the regional support services informally collaborated to support a client with particularly high needs. The informal collaboration included local not-for-profit cancer organisation, social work staff, and the RBN, who shared the heavy burden of care across organisations.

*"And so it became very clear – we had to set up a system whereby ... we had to support each other and try and share the load of this particular client..." RBN5*

Furthermore, the not-for-profit cancer organisations worked collaboratively with RBNs by providing information resources free-of-charge for RBNs to provide to women. This expanded the capacity of the RBNs' nursing practices:

*"The Cancer Council ... providing me with their information booklets is very very helpful, because if they didn't do that then I certainly don't have the resources to be able to purchase those to be able to give out."*  
RBN3

The collaborative linkages made through the Breast Nurse Network (described in the Peer Support section on page 224) strengthened their leadership efforts, and

expanded the benefits state-wide. For example, one nurse took the initiative to develop a breast care clinical pathway form, and all the RBNs state-wide were trialling them in their practices. In another instance, a nurse took the lead to organise a renowned Australian holistic specialist to speak at a forum conveniently in the middle of the state. All RBNs were then able to advertise the opportunity to their clients, and gain the benefit for their own nursing practice as well.

*“It was really exciting for us, the breast nurses to bring down (holistic specialist). I found that absolutely fantastic, not only to be there with all these women ... but also for my own development and understanding ... . So things like that all help to broaden my knowledge, my understanding and therefore to bring that back and share it with the women that keep coming through.” RBN3*

Additionally, RBNs described informally working together to support women, and provide a reliable referral source for specialist clinicians. In one region this was within the same organisation. Significantly, in another region, this collaboration between RBNs was across ‘competing’ organisations. This was perceived to increase clinicians’ confidence in the availability of RBNs, and ensure an RBN was available to any woman.

*“(RBN name) set up referral system within the private sector, so that if a woman comes in [she] will get to see a breast care nurse, and if she’s not available I’ve sort of said, ‘Look, I can come and visit any woman’ so that I make sure that they’re referred into the system...” RBN5*

#### **8.2.2.2. Employing organisation**

The socio-cultural contextual features of the employing organisation influence the parameters and focus of the RBN service and the nursing practices of the RBN. RBNs identified the type of employing organisation and the level of genuine support of the RBN role as key features impacting their experiences in the role.

#### 8.2.2.2.1. Organisation Type

RBNs considered that the type of employing organisation shaped the focus of RBN nursing practices. Hospital-based RBNs said they consulted more regularly on-site, lacking the freedom that *Community RBNs* conveyed to consult with women in their home. Similarly, *Community RBNs* identified benefits of a community base:

*“... It's very beneficial working in the community, being able to go in and out of hospitals and the feeling that we can see clients wherever they want to see us.” RBN1*

One *Private Hospital RBN* described her need to justify her RBN hours due to pressures from administration and management. She conveyed her need to demonstrate that her role was worthy of the organisation's monetary input.

*“And my need (to) justify, the amount of time that I was doing because it was a service that the hospital was supplying without them getting any sort of monetary... it was only sort of appearing on one side of the ledger as far as the business side of things so I felt that there was a bit of pressure there to, minimise and prioritise what I was doing.” RBN2*

These beliefs and perceptions appear to have come from this RBNs need to provide detailed reports of her RBN activities, and the lack of feedback received from management about the role or the reports presented.

*“... I gave him regular reports on the number of hours that I spent going in consultation and in documentation, referrals etc but I didn't ever get any feedback... Hmm. So it wasn't so much what was said, but it was probably what was unsaid basically.” RBN2*

The other *Private Hospital RBN* also conveyed the sense that the RBN role did not measure up monetarily, and that the value-added positions such as the RBN were the ones that would be folded.

*"I don't believe that the two organisations that I've worked for support the concept. Because it's all measured against work hours. If you don't produce or don't have – it's the value-added that I think they just cut. That's the reality." RBN5*

#### 8.2.2.2.2. *Genuine Support*

RBNs considered the employing organisation's level of genuine (rather than superficial) support for the RBN role influenced breast nursing practices. RBNs perceived genuine support from the hours allocated to breast nursing, the nursing level of the position, support for ongoing education, and the freedom to pursue what the nurse sees as important along with the money or resources to make 'extras' possible.

RBNs described their awareness of their employing organisation's true support, or lack thereof, for their nursing services. A few nurses' descriptions clearly painted the picture of individual nurse's need to carry the role and service, without genuine organisational support.

*"From an organisational point of view, I knew that there was commitment to the role, but I think it was shallow. ...I was able to independently go and do that, and support the women but realistically the organisation, I don't believe, was interested in ever progressing the role." RBN5*

The level of support for the RBN role from the employing organisation ultimately determines the practical working parameters within which the nurse provides care. The level and conditions created by the employing organisation affected RBN's perception of organisational support. Allocated RBN hours, along with the eligible clients, influenced a nurse's capacity to provide support across the full intervention timeframe. The fit between allocated RBN time and workload pressures influenced whether a nurse was able to provide the full continuum of care across time. Regular hours and a role considered to be 'core business' conveyed organisational

support. Also, the nursing level of the RBN position was seen as a proxy for the respect the employing organisation had for the role.

Another important working condition described by RBNs as having resulted from genuine organisational support was the formal backing of their ongoing education and professional development. Nurses described their need to keep abreast of best practice and keep invigorated, and envisioned professional development as a critical factor to enable this. One RBN described pursuing professional development in her own time when she perceived a lack of organisational support.

*“I had to justify regularly exactly what I was doing and the number of hours ... not so much as far as the number of hours I was giving to the woman, but I felt that ... I needed to ... [justify] my own learning needs. [As a result, my professional development] was basically done in my own time.” RBN2*

All RBN's described a lack of formal professional supervision and support from within their organisations, and one RBN pointed to this in emphasizing the special importance of ongoing education for them.

*“If we don't have that sort of professional supervision then I think it's very dangerous. So that's why it's particularly important for me to keep up my own professional education. So if I can see what other people are doing, listen to other people who have much more experience and knowledge, especially in the psycho-social area, then I find that very beneficial, because it helps me understand what the patients need and why people do the things they do, and why people feel the way that they do, and what can I do to actually help them...” RBN3*

Two RBNs expressed their desire for support from their employing organisations to 'do the extras'. One RBN wanted the organisational support, in the shape of freedom and resources, to go beyond the standard RBN intervention.

*"I like to be able to do more. I'd like to be able to say that every year we have (holistic cancer specialist) come to Tasmania and do her workshops and that those workshops would be freely available to the women that I come in contact with. And every year we could do a Living With Cancer program and pay the naturopath, to come along and do that, but every year I'm always looking for finances, resources, putting in submissions to people - it drives me nuts." RBN6*

She did express that the freedom to pursue her role as she saw fit was enabling.

*"(Manager) doesn't say ... to me, ... "What are you doing? Where are you going? What's all this about?" She just says, "Go and do it.", and it's absolutely fabulous." RBN6*

#### 8.2.2.2.3. Political Conditions

Changing political and/or structural conditions of the employing organisation were described as undermining previous foundations of genuine support. For example, one RBN role was initially set up as a specialist position, then as the private hospital changed ownership, the role was effectively demoted in its nursing level and pay.

*"Initially it was... a specialist nurse role. And that was the way it was looked at, that was the way it was initially set up ... but as the history of the hospital changed it evolved. ... The fact that, initially I was paid as a specialist nurse, and then it was demoted as a certificate nurse." RBN2*

In the face of perceived limited employing organisational support, this RBN chose to resign rather than advocate for greater support by 'fighting the organisation'.

*"You're probably wondering why I resigned from the position, but I could see ... it wasn't going to be supported by (organisation name). ... The writing was on the wall here and I didn't want to have to fight that battle." RBN2*



In summary, the socio-cultural contextual features of people and services influenced nursing practices. The findings demonstrate the positive impacts of acceptance and support, connections and collaborations, the negative impacts of divisions and disputes, and the potential for norms to positively or negatively influence nursing practices. Also, the type of RBN employing organisation and their perceived level of genuine support for the RBN role influenced the RBN care provided to women with breast cancer. The employing organisation set the tone for the role with its focus, the parameters and level of the RBN role, and the freedoms provided. RBNs perceived the genuine support for the role through the organisation's support of ongoing education and providing for the extras.

The wider healthcare context in which the RBN and woman engage, affects the RBNs ability to support women's supportive care needs being met. RBNs conveyed how physical and psychosocial contextual characteristics affect the RBN processes of care and outcomes for women with breast cancer. Physical setting features of time and space, sites and services, and employment parameters influenced care processes and outcomes. The psychosocial setting features of people and services and of the employing organisation were detailed by RBNs to impact interventions and outcomes.

### **8.3. Summary of Learnings from Nursing Insights**

This and the previous chapter (Chapters Seven and Eight) conveyed RBNs perceptions of the factors influencing breast nursing practices and client outcomes (directly or indirectly). RBN's reported that their capacity to positively influence women's journey with breast cancer was influenced by the interacting characteristics of the women, the nurse, the intervention and the context. Each of these characteristics influences the outcomes, as well as each other. The findings demonstrate clearly that RBNs perceive their breast nursing practices and clients' supportive care outcomes are influenced by the combination and interaction of factors that can be classified as client, intervener, intervention, and setting characteristics.

The care processes and care characteristics (i.e. the manner in which care was provided) were deemed important. Care was provided using RBNs' high level interpersonal and assessing skills. RBNs care embodied a client-centred focus, with a holistic and empowering approach, with nurses portraying an openness and accessibility to women. Care Processes described by RBNs were categorised as holistically assessing, providing a pivot point, linking, providing information and/or 'translating', dealing with emotions and coping, supporting decision making, 'filling the gap', advocating, client finding, collaborating, and peer support.

Both the RBN and the woman influenced breast nursing practices and client outcomes. As intervener, the RBN influenced nursing practices and outcomes through their personal and professional characteristics. RBNs professional experience and confidence as well as their comfort in dealing with emotions were of note. The client's personal, health, and resource factors influenced care and outcomes too. The client brought 'who they are' to the breast cancer experience, as well as their individual health status, disease and treatment profiles. The women drew on the personal, social, and financial resources at their disposal while shouldering their own personal and professional responsibilities.

Also the physical and socio-cultural setting features influenced breast nursing practices and outcomes for women. The proximity of cancer services, availability of consultation areas, and client-base were all influential objective physical features. RBNs working conditions, including employment hours and conditions, had significant implications on RBN care provision. The socio-cultural features of acceptance and connections, and divisions and disputes had very direct impacts on care provision as did collaborations. Additionally, the employing organisations type, genuine level of support and political conditions moulded RBNs experiences and shaped the care RBNs provided.

In conclusion, these two chapters explained how RBNs described their interventions and the factors RBNs perceive influence breast nursing practices. Thus, the chapters addressed *what* rural breast nursing entails as well as *why* breast nursing

practices are as they are. These findings in combination with the previous quantitative results chapters provide insights into breast nursing practices in rural contexts. The next chapter (Chapter Nine) integrates these findings to develop a conceptual framework for breast nurses' practice in rural settings.

## **Chapter Nine: Synthesis – Developing a Conceptual Framework for Breast Nurses’ Practice in Rural Settings**

This study has examined rural breast nursing practices, their client’s supportive care outcomes, and the key factors that influence how RBNs undertake their work. The study is underpinned by an intervention conceptual framework within a pragmatic philosophical perspective. Specifically, this study has intended to identify factors responsible for enabling breast nursing practices to be successful in ultimately producing favourable outcomes for clients. This chapter provides a synthesis and discussion of the findings from the previous four chapters towards meeting the research aim: *to advance knowledge of rural breast nurses’ practice within real world contexts.*

The pragmatic approach combined with the intervention conceptual framework has provided the means through which to explore rural breast nursing practices. Pragmatism supported the use of diverse ‘ways of knowing’ in order to develop a depth of understanding, while the intervention framework provided a structure to consider the influences of client, RBN, intervention, and context on breast nursing practices and client outcomes.

The two key findings from this study contribute to addressing the research question: *What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?* Firstly, the development of a conceptual framework for rural breast nursing practice emerged from the findings to answer the overarching research aim. The intervention conceptual framework allowed this study to shed

light on aspects of breast nursing which have previously received little attention in the literature, namely the strong influences of specific contexts and RBNs. Rural breast nursing practices are identified as context and RBN-dependant services. That is to say, the individual RBN and the local context shape the interventions provided. Although the influence of individual women on interventions and outcomes has been identified and acknowledged, the BN scientific literature has been minimal with regards to the influences of setting features and RBN characteristics on nursing practices and outcomes. The individual nurse impacts the service based on *what she knows, who she knows* and *who she is*, with local contextual knowledge being particularly important. The context is influential in the proximity of services and clients, the extent of organisational support, support from the wider health system, and the availability of other services. Together, these findings provide both a description and explanation of rural breast nursing practice.

The significance of the 'availability and accessibility' concept to the success of RBN services is the second key finding from this study. This concept emerged as a cross cutting theme across the developed conceptual framework impacting the success of RBN services by hindering, enabling and generally shaping nursing practices. The 'available and accessible' concept arose as relevant for clients, RBNs, and the wider healthcare system.

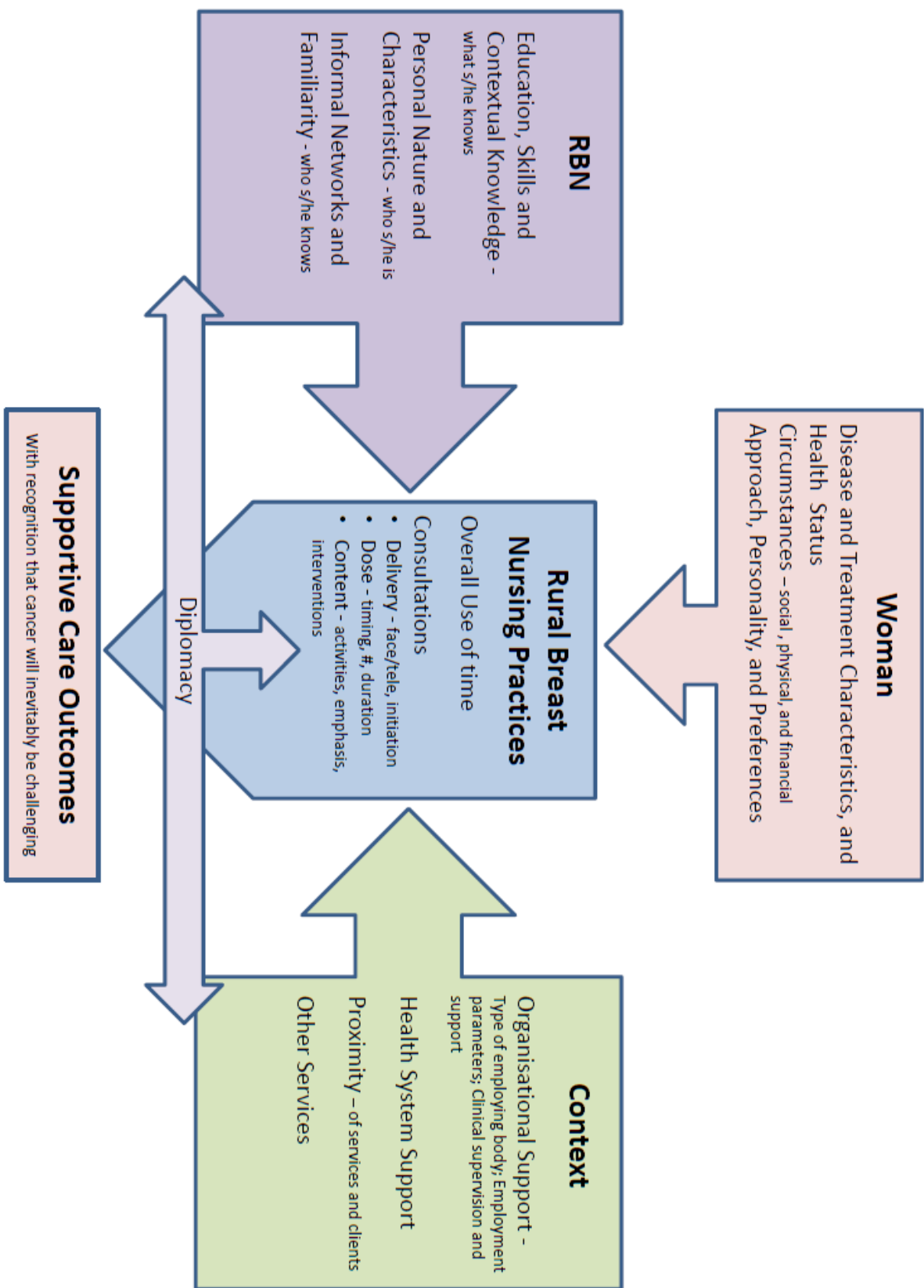
## **9.1. Rural Breast Nursing Practice – A Conceptual Framework**

Historically, the individual nurses and the distinct settings have not received appropriate attention, as clients have, in their influences on breast nursing practices and outcomes. In contrast, this study examined the characteristics of nurses and settings which impacted nursing practices. By using the intervention conceptual framework as a theoretical framework for examining RBN services, the influence of individual RBNs and discrete settings on rural breast nursing practices has been better understood.

By moving away from a narrow focus on the intervention, and instead viewing breast nursing in a health services framework, a wider view was taken to consider how supportive care outcomes for women are brought about. The utility of this conceptual framework is supported in this section by linking the framework to consistent findings elsewhere in the scientific literature, whether key findings or footnotes. Furthermore, it contributes to building theory to guide rural nursing practice which has generally been limited internationally (Bushy, 2002).

This conceptual framework for RBN practice builds on Sidani and Braden's (1998) generic nursing intervention conceptual framework. However, the framework provided here gives greater emphasis to the importance of distinct contexts and individual RBNs on rural breast nursing practices and outcomes for women with breast cancer. The conceptual framework for breast nurses' practice in rural settings is presented visually at Figure 12.

Figure 12: Conceptual Framework for Breast Nurses’ Practice in Rural Settings



Rural breast nursing practices were identified as context and RBN-dependant services, as identified in Chapters Seven and Eight. The nurse impacts the service based on her individual characteristics, with contextual knowledge consistently arising as an important theme. Discrete contexts shape breast nursing practices by the proximity of services and clients, organisational support, support from the health system at large, and the availability of other services.

Below the conceptual framework is discussed in relation to the findings of this study, and supported by findings within the broader literature. Additionally, comparisons are made with the Sidani and Braden's (1998) generic nursing intervention framework throughout.

### **9.1.1. Individual RBNs**

Each RBN is unique. Furthermore, she is more than her job title and qualifications. Instead, the RBN comes with – and continues to develop - her own set of professional and personal experiences, personality traits, and relationships. This individuality impacts how she chooses to, and is able to, undertake her RBN work, as well as how women respond to her. Individual RBN characteristics determine how the nurse embodies the RBN role, and can enable and/or inhibit the implementation of quality interventions. The interview findings of this study identified the RBN characteristics important in shaping nursing practices and outcomes. These characteristics are grouped by *what she knows* (education and skills), *who she knows* (networks and familiarity), and *who she is* (personal nature and characteristics). Importantly, contextual knowledge emerged as significant for both *who* and *what* the RBN knows.

The RBN's potential influence on nursing practices is mirrored in the broader theoretical literature as well. Consistent with the Sidani & Braden framework (1998), this model acknowledges the potential influence of RBNs professional and personal characteristics. Their framework identifies direct and indirect effects of the intervener on the outcomes. Specifically for example, participants may respond



to the intervener rather than the intervention (causing direct effects on outcomes), and/or interveners may implement the intervention variably (causing indirect effects on outcomes) (Sidani & Braden, 1998). “Thus, the success of the intervention may be related to the characteristics of the intervener or of the intervener-participant interaction and not necessarily to the nature of the intervention delivered” (Sidani & Braden, 1998, p.91). Sidani and Braden (1998) highlighted the importance of having different nurses applying interventions in studies in order to identify interveners’ effects on outcomes.

#### **9.1.1.1. Education, Skills, and Contextual Knowledge**

Advanced skills, in-depth knowledge, the use of skills and knowledge in previous roles, along with contextual knowledge all play a part in shaping rural breast nursing practices. Clearly, the RBN is impacted by *what she knows*, namely her professional education and skills. For example, having completed relevant accredited breast care nurse coursework is certainly valuable for RBNs, as is in-depth knowledge of oncological and surgical treatments, procedures, outcomes, and side effects. In this study, lack of core knowledge and skills was identified as negatively impacting one RBN’s confidence in addressing related issues and queries for clients.

Furthermore, having used the same or similar skills and knowledge in previous roles enhanced RBNs’ confidence and command of RBN processes of care. This in turn led RBNs to organise their role around what they were most familiar with. Their work in previous fields heightened their awareness of client’s needs in those areas, and they often addressed these areas proactively. For example, in this study two RBNs identified how their experiences in stomal therapy informed their work in addressing the diverse needs of women with breast cancer. Meanwhile, another RBN identified that her limited oncology experience impacted her confidence and ability in the RBN role. While previous skills are certainly beneficial, it is important to acknowledge that skills can also be developed in the role. For instance, a *Private Hospital RBN* expressed her increasing confidence and abilities in addressing sexuality issues over the course of the study. Similarly, the literature acknowledges

that professional and life experiences are important in preparing those in supportive care positions to carry out their roles effectively (Farber, et al., 2002).

What an RBN knows is not limited to skills and education, as contextual knowledge was also a key factor influencing how RBNs went about their role in this study. Familiarity and experience with local services and systems of care proved valuable for RBNs in their work to support and empower women. For example, awareness of relevant local community services and inclusion criteria allowed RBNs to refer women appropriately. The importance of knowledge related to the distinct healthcare context also relates to *who RBNs know*, which is discussed in the Informal Networks, and Familiarity section on page 280.

The literature echoes the importance of BN education, specifically the knowledge and understanding around a wide range of issues affecting women with breast cancer, as well as the need for advanced nursing skills. Australian competency standards indicate advanced knowledge is needed of women's needs, preferences, and circumstances across the full continuum of care (Yates, et al., 2007). Moreover, BNs require advanced nursing skills as they implement complex interventions composed of multiple components (Sidani & Braden, 1998; Yates, et al., 2007). The qualifications, preparations, and experiences of BNs impact how s/he undertakes the role, and that variations in nursing practices reflect these differences (Ream, et al., 2009; Victorian Centre for Nursing Practice Research, 2001). For example, the authors of the mixed methods study of cancer nurse specialists concluded that nurses undertook the role in different ways partially based on variations in the nurses' qualifications and experiences (Ream, et al., 2009). Similarly, varied nurses' characteristics - such as educational and experiential background – are identified as influencing the degree to which individual nurses can achieve a role's aspired outcomes (Woodward, et al., 2005).

Thus, the literature supports the idea that BNs require relevant knowledge and advanced skills. Yet this emphasis is often limited to the BN literature that discusses knowledge and levels of practice, such as competency standards and educational

standards (Yates, et al., 2007), whereas many BN studies often neglect this information from their reports. However, case studies with fewer participants more often report the BNs training and experience (for example not in: Eley, et al., 2008; yet in: Jones, et al., 2010). The omission of descriptions of nurses' professional education and skills when describing research interventions and outcomes suggests these characteristics are not recognised (nor demonstrated) as important.

Furthermore, the BN literature has similarly not reflected the importance of contextual knowledge to support effective breast nursing practices. However, the importance of contextual knowledge has been identified in the wider rural nursing literature. For instance, findings from this study are supported by claims that rural nurses "greatest attribute is knowing about formal and informal community resources and how to access these for client systems" (Bushy, 2002, p.109). It may be that contextual knowledge is indeed more important within the rural context. Again, the importance of contextual knowledge is discussed further in the Informal Networks, and Familiarity section.

As RBNs undoubtedly require advanced knowledge and skills specific to supporting women with breast cancer, there are clearly implications for rural nursing based on these requirements. Firstly, rural areas are likely to find it more challenging than more populated areas to find suitable applicants with the range of breast cancer specific advanced skills, education, and knowledge required. Indeed, the literature highlights a shortage of appropriately skilled rural RNs in Australia (Mills, et al., 2005), and more broadly there are difficulties in attracting high quality practitioners to rural areas (Chenoweth, 2004). Therefore, targeted professional development for rural nurses embarking on breast nursing may be useful to effectively up-skill traditionally generalist rural nurses in this specialist nursing realm.

Alternatively, if a BN comes from another area with the required professional attributes, she will lack important contextual knowledge, and likely be considered an 'outsider' for some time. Thus, breast nurses new to rural communities need to allow time to gain acceptance and contextual knowledge (Long & Weinert, 2010).

However, contextual knowledge, nursing skills, and breast cancer specific knowledge can be learned.

Secondly, the importance of continuing professional development is evident. As breast cancer treatment and care continue to evolve, RBNs must have up-to-date knowledge of these practices and their implications for women. Yet, rural nurses find professional development opportunities more difficult to access than their metropolitan based counterparts (McCoy, 2009; Penz, et al., 2007). Rurally-based nurses face difficulties in continuing professional development and maintaining professional competence, often due to financial and time constraints, the additional travel time and distance, and inhibitive work schedules (McCoy, 2009; Penz, et al., 2007). However, supportive and encouraging organisational environments can facilitate rural nurses' participation in continuing professional development, for example by supervisor and financial support (Fahey & Monaghan, 2005).

The lack of continuing education opportunities emphasises the importance of RBNs' professional networks as an important learning resource. Yet, with many rural areas lacking formal multi-disciplinary teams and indeed local specialists, this can further challenge efforts to stay informed. Additionally, RBNs are often isolated from BN colleagues. Nonetheless, the RBNs in this study emphasized the importance of attending national BN conferences, as well as learning from their BN colleagues at state-wide network meetings to stay up-to-date with knowledge and practices. Similarly, peers were identified by rural nurses as the most important source of information and education (Scharff, 2010). Likewise, the rural nursing literature signposts "networks that link together nurses practicing in distant rural sites are particularly useful, both for information exchange and for mutual support" (Long & Weinert, 2010, p.15). RBNs' reliance on one another is not surprising given the lack of professional support for rural nurses identified in this study as well as elsewhere in the literature (Mills, et al., 2005). Thus, peer support and educational networks may be more important for rural than urban BNs.

### 9.1.1.2. Personal Nature and Characteristics

This study has shown that an RBN's personal nature and characteristics, although often disregarded in the BN scientific literature, have the potential to shape nursing practices as well as outcomes for their clients. The nurses' comfort with sensitive topics, such as emotions, sexuality, and death, has important implications on their ability and inclination to utilise effective skills in breast nursing. Additionally, RBNs dedication to the role and/or their clients can lead them to work additional hours to fulfil the role when workloads are not manageable within allocated hours. Furthermore, RBNs noted their clients responding to their personal characteristics (perceived age for example), thereby potentially influencing outcomes.

The findings from this study highlighted that *who the RBN is* impacts how the RBN chooses to - and/or feels comfortable in - enacting the role. An individual RBN's confidence and comfort in their skills and themselves impact their inclination to undertake certain interventions, even when a base level of knowledge may be present (through a education course for instance). This was reported in Chapter Seven. For example, in this study one *Private Hospital RBN* openly identified she was not comfortable with her own emotions and therefore found confronting her clients' emotional issues challenging, and thus, usually did not broach such topics. This was consistent with the findings of this RBN's consultation practices reported in Chapter Six, meaning this RBN addressed emotional issues with her clients less frequently than other RBNs.

Conversely, RBNs raise issues they are comfortable with, directly with their clients. This was particularly evident in relation to sexuality issues in this study. Some RBNs addressed possible sexuality concerns directly with their clients, while others approached it indirectly, or waited for clients to raise issues. To some degree, this can be construed as a matter of style, but it may also reflect a level of comfort with the topic, as well as a clear indication to clients that the topic is relevant and 'open for discussion'. Thus, RBNs who raise sensitive issues directly may encourage their clients to initiate discussion on such topics at another time.

This is an important finding from this study, as regardless of how common it is to be personally challenged by aspects of the BN role; it has important implications on hiring practices. Moreover, it may be more relevant to employing BNs in rural areas, where the list of applicants may be short. This suggests it is important to consider an applicant's suitability to the role on a personal level - for instance her comfort in dealing with emotions, death, and sexuality - and not simply on a professional level. Yet, it is possible for RBNs and BNs more generally to develop this personal capacity. For example, The Cancer Council runs sexuality workshops to assist clinicians to develop the skills to broach this sensitive topic (TCCNSW 2002).

Beyond the personal nature of RBNs, personal characteristics are identified as influential in the client-nurse relationship. Specifically, one RBN in this study identified her relatively younger age made some of her clients and their partners uncomfortable. This finding mirrors Sidani and Braden's (1998) conceptual intervention framework which highlights the direct effects that interveners can have on outcomes, based on how clients respond to nurses. Indeed, other nurse characteristics related to perceived physical appearances and demeanour may also be influential in shaping clients' responses. Thus, it is important that RBNs consider that how they 'present' can impact the ease of their clients in sharing and discussing personal and private issues.

Although the personal nature and characteristics of BNs have generally been taken for granted within the BN-specific literature, there are some references to their effects within the published literature. Not surprisingly, the RBN's personal attributes likely to influence the success of their interventions are often specifically noted in studies where there was only one nurse providing the service or intervention (for example: Eley, et al., 2008). Additionally, specific attributes are identified as positively impacting specialist cancer nurses work. For example, assertive confidence by specialist nurses was seen to positively affect the functioning of multi-disciplinary teams (Ream, et al., 2009).

Support for the potential influence of nurses' nature and characteristics on nursing practices and outcomes are found in the wider nursing, supportive care, and medical literature. The literature identifies the importance of nurse consultants holding appropriate personal characteristics as they influence the nurse's ability to undertake the necessary practice components thereby bringing about positive outcomes for their clients (Woodward, et al., 2005). Similarly, clients previously identified the 'right' medical provider for people with chronic conditions to be one who demonstrates commitment to an in-depth trusting relationship, personal rapport and understanding along with competence (Martin et al., 2009). Just as this study found comfort with emotions and sexuality to be particularly important, nurses' emotional intelligence is correlated with clinical decision-making and patient care (Bulmer Smith, et al., 2009).

Furthermore, a systematic review confirmed the effectiveness of medical providers is improved when they present with a warm, friendly, and reassuring manner (Blasi et al., 2001). The authors of a cancer and palliative care nurse personality profiling study surmised that the nurses' personal characteristics identified (e.g. empathetic, open, insightful, and group oriented) would benefit the nurses in a caring occupation which relied on teamwork (Gambles et al., 2003). Additionally, the literature highlights rural nurses have benefited from "a rich heritage of resilience, resourcefulness, adaptability and creativity" (Bushy, 2002, p.109). Thus, the findings of this study contribute to the literature about the influence of RBNs' personal nature and characteristics on nursing practices and outcomes.

#### **9.1.1.3. Informal Networks, and Familiarity**

Individual RBNs' relationships with key players, both clinicians and 'gatekeepers', had a significant impact on their breast nursing practices, as well as RBNs' influence on the wider system. Thus, *who she knows* impacts rural breast nursing practice and client outcomes. For instance, an RBN was able to prepare clients for the unique styles of different specialists. While familiarity with key individuals assisted RBNs in their work to support women in their cancer journey, it was also important

that individual RBNs were known by the key players. In this study for example, when an RBN had positive relationship with ward staff and in particular managers, she was able to access lists of surgical patients who were potential clients. Similarly, a positive trusting relationship between an RBN and surgeon led to the RBN being given the surgeon's direct mobile number. Moreover, these relationships 'opened doors' across traditional organisational boundaries.

Just as RBNs used *what* they knew to guide their nursing practices, RBNs also utilised their networks or *who they knew*. Indeed, consistencies were found in this study between who individual RBNs knew, and their breast nursing practices. That is, RBNs organised their role around what they were most familiar with. For instance referral to community nursing was more common if RBNs had worked in that area. Also, RBNs with good working relationships with specialists described ringing them when they had queries, such as why a certain treatment plan had been chosen for a client.

Clearly, formal networks are easier to assess and describe than informal networks and relationships. This may be why the literature is confined to discussing BN networks as their participation and involvement in formal multi-disciplinary teams (e.g. the role of the BN in multi-disciplinary teams, or the impact of team composition including BNs (Amir, et al., 2004; Haward, et al., 2003). In contrast, this study highlights the importance of professional relationships and informal connections as they are influential in shaping rural breast nursing practices.

Nonetheless, the knowledge about BNs formal networks can be applied to the informal networks which are more common in rural areas. The literature supports the positive impact that familiarity and positive relationships amongst specialist nurses and specialists can have. Specifically, levels of trust and integration within a multi-disciplinary team are enhanced when a specialist nurse had worked at the site or within the system previously, and embodied an assertive confidence (which comes with experience) (Ream, et al., 2009). Thus, specialist clinicians' familiarity



with an RBN's skills and personality, based on a shared professional history, can be beneficial.

The wider rural nursing literature also lends weight to the importance of networks for rural nurses. These networks are sometimes described as linkages, connectedness or social capital (Conger & Plager, 2008; Lauder, et al., 2006; Mueller & MacKinney, 2006). Internationally, the informal and formal networking of rural nurses has been identified as facilitating the provision of a coordinated care giving (Bushy, 2002; Mueller & MacKinney, 2006). The importance of 'connectedness' for nurses has also been identified in rural advanced nursing practice (Conger & Plager, 2008). Specifically, "elements leading to connectedness included development of support networks, relationships with urban healthcare centers, connections with local communities, and support through electronic means" (Conger & Plager, 2008, p.24). While the literature identifies that rural nurses contribute to the social capital of their communities (Lauder, et al., 2006), this study extends this understanding by demonstrating rural nurses are empowered by their own individual social capital to influence care practices and outcomes.

Indeed, the informal networks of BNs may be differently important in rural settings.

"Although whom one knows can be important in any setting, the distinction between rural and urban dynamics of whom one knows is that the urban setting whom one knows is more likely to be related to competitive advantage, whereas in rural settings whom one knows is more likely to be related to cooperative advantage." (Scharff, 2010, p.252)

Thus, the importance of informal networks and relationships (i.e. the human side of contextual knowledge) is especially apparent in rural contexts. Literature highlights how relationships are vital to successful advanced nurse roles (Woodward, et al., 2006). The importance of informal community connections to rural practitioners has been noted (Chenoweth, 2004). The importance of local support networks and

collegial relationships for practical and emotional support of clinicians is echoed in the rural palliative care literature (Robinson et al., 2009).

Therefore, an RBN's relationships and networks are important in shaping her nursing practices and influencing outcomes for clients. When assessing RNs suitability for and capacity in the RBN role, the quality and strength of her relationships with clinicians and 'gatekeepers' is important. These findings indicate the value of RBN's familiarity and experience in the local context, and the clinicians' familiarity with, and positive assessment of, the RBN's skills, knowledge, and general approach. Consequently, it may be useful for specialist clinicians to participate in the RBN selection process.

In summary, the RBN's influence on the way she practices the role is evident in this study, and has been echoed elsewhere in the literature. *What an RBN knows, who she knows, and who she is* shapes nursing practices. Importantly, contextual knowledge is very relevant to both *what* and *who she knows* in their influence on shaping nursing practices. The context's influence on breast nursing practices will be argued after the challenge of diplomacy is discussed - which sits at the nexus between the RBN and the context.

#### **9.1.1.4. The Challenge of Diplomacy**

At the interface of the RBN and the context, there is a challenge for RBNs to navigate. The challenge is for the RBN to remain 'in favour' - or indeed initially build trust - with key specialist clinicians and gatekeepers (and their own organisation), whilst trying to support their individual clients and their clientele more generally. In this study RBNs described themselves 'walking the fine line' while attempting to advocate for women while 'keeping the peace' with specialists, and explained they needed to be cautious. RBNs clarified they could either 'get their foot in the door', or 'get sealed out' depending on the relationships with key players, and if they had put anyone offside, i.e. 'ruffled any feathers'. They described the need to work in a

way that is acceptable to the specialist community and their organisation, or face a decline in trust.

Negative working relationships between the RBN and key members of the healthcare team are thought to decrease referrals. A souring of the relationship between the RBN and the employing organisation potentially means less freedom for an RBN to drive nursing practices. Thus, 'ruffling feathers' could have severe consequences on rural breast nursing practices. This challenge is echoed in the Australian literature with descriptions of clinicians being uncertain about a new BN, and whether the nurse might provide contradictory information and raise issues clinicians might not want raised (SBN Project Team, 2000).

The RBN's personal nature and characteristics along with her informal networks could buffer the threat of losing support for the individual nurse and the RBN service. The established trust, based on the experiences of working together and a familiarity with one another, is an important safeguard. Specialist clinician's fears of the contradictory information that might be provided by BNs, or issues being discussed which they might not want raised, are thought to be likely " 'if you got the wrong person in the job' " (SBN Project Team, 2000, p.47).

A consistent theme for both rural and urban BNs is the necessity of having, or quickly establishing, a credible professional identity. RBNs in this study expressed the importance of this, and this has been echoed elsewhere for rural practitioners (Chenoweth, 2004). Similarly, the National SBN Demonstration Project highlighted the importance of specialists' confidence and trust in the SBN's professional knowledge, skills, and practice (SBN Project Team, 2000).

The necessity and benefits of nurses establishing trusting relationships with other providers and 'gatekeepers' are echoed in the wider literature. Emotionally intelligent nurses are identified as inspiring trusting relationships "because they understand the nature of nursing, patient care and the environmental impact of practice in relation to nurses' work" (Bulmer Smith, et al., 2009, p.1631).

Furthermore, within the rural context “nurses must be flexible and effective team players” (Bushy, 2002, p.109). Relationships and internal trust networks are vital to enable the achievements of nurses (Woodward, et al., 2006). Furthermore, the literature echoed the need for nurses “to be careful in their choice of strategies to deal with the traditionally medically dominated culture” (Woodward, et al., 2006, p.272).

Thus, key player’s familiarity with and trust in the nurse’s skills, expertise, and style of working can bolster their reassurance that they are comfortable with the RBN’s nursing practices with their shared clients, and in the system at large. However, this appears to continue to be a challenge - although not as significant – for established nurses. Therefore, the importance of RBNs having and *maintaining* good working relationships with specialist clinicians and ‘gatekeepers’ cannot be underestimated, and nursing practices are influenced by the need to ‘keep the peace’. This, along with the importance of informal networks suggests it is important for nurses to devote time to relationship building and maintenance (Millard et al., 2006).

### **9.1.2. Discrete Contexts**

The setting features influence rural breast nursing practices through the practical conditions of healthcare and social settings, as well as organisational and individual relationships, priorities, and values. The interview findings in combination with the breast nursing practices identified in this study, clarified the importance and influence of organisational support, wider system support, proximity (i.e. the location of cancer services in relation to the RBN service and client), and the availability of other services to the interventions provided by RBNs. Whilst other terms are used in the literature at times to convey context (e.g. site and environment), these findings were supported by the wider literature.

Correspondingly, Sidani and Braden’s (1998) intervention conceptual framework recognises the potential influence the setting characteristics can have on client outcomes. Additionally, they warn of ignoring settings features. “If the

intervention is delivered in the same place, under the same conditions, across all participants, the setting is constant, and its effects are potentially confounded with the treatment effects” (Sidani & Braden, 1998, p.101). Thus, in order to appreciate the potential influence of the context of care on outcomes, the intervention should be examined under multiple settings. This is precisely what was done in this study.

Sidani and Braden’s (1998) conceptual intervention framework and this conceptual framework for rural breast nurses’ practice are consistent in their recognition of the potential influence of physical and sociocultural contextual features on nursing practices and client outcomes. The generic nursing framework considers the setting in terms of physical and psychosocial characteristics. Physical and sociocultural<sup>54</sup> features are also recognised within this RBN conceptual framework, which provides more detail by naming elements of the context which are useful to consider for rural nursing practices (namely, the employing organisation, wider health system, and other services). These contextual elements in turn have physical and sociocultural features which are then considered and explained to be important within the conceptual framework.

Consistent with the findings of this study, the rural medical literature also identifies the major influence of context. “Practitioners develop an appreciation of how space and place affects both clients’ lives and their own practice” (Chenoweth, 2004, p.279). Furthermore, the importance of context is also reiterated in the rural nursing literature. This literature highlights how rural nursing practice is contextualised (Howie, 2008a). That is, rural nursing practice is shaped by its environment (Puskar, et al., 1996). Furthermore, the most major influence on the rural nurse role is the context of practice (Mills, et al., 2010). Thus, the context “can facilitate or impede the implementation of the intervention and consequently the achievement of outcomes” (Sidani & Braden, 1998, p.102).

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<sup>54</sup> This RBN conceptual framework modifies the Sidani and Braden (1998) terminology of psychosocial to sociocultural features which resonated more clearly with the findings of this study.

### 9.1.2.1. Organisational Support

The organisational support and commitment to advanced nursing roles enables the benefits of these roles to come to fruition (Woodward, et al., 2006). Furthermore, the employer, and the organisational unit where the RBN sits, influences the nursing practices in a myriad of ways. The organisational support of the RBN role is embodied on many different levels which influence nursing practices. Some influences directly impact practices, while others are indirect. Just as some influences are subtle, while others are overt. This was resoundingly confirmed by the RBNs in this study.

Specifically, this study highlights the influence of the type of employing body, the employment parameters, and the provision of clinical supervision and support. The type of employing body, along with its individual priorities and values, directly and indirectly impact rural breast nursing practices. This study also shows that the key employment parameters the employing body imparts on the role include the hours allocated to the role, the nursing level ascribed to the position, and the position description. The provision of essential resources also has significant impacts on nursing practices. Furthermore, the provision of professional clinical supervision and support suggests an understanding of the need to support the RN emotionally and psychologically.

The type of employing organisation, and where within the organisation RBNs were physically and administratively situated, influenced nursing practices. RBNs described organisational influences on when in the breast cancer journey nurses were directed to support women. For example, the *Community RBN Site* most often consulted with clients later in the journey (1-6 wks post-operatively) as compared to the hospital based RBN sites who were more likely to consult with clients peri-operatively. This finding was mirrored in the literature. What BNs do “was often determined by the position each held in the employing institution and the length and breadth of their involvement with the women and their families”

(White & Wilkes, 1999a, p.10). Additionally, a recent journal article highlighted the varying scope of breast nursing practices under various practice contexts (Jones, et al., 2010).

Additionally, employing organisations and managers shape nursing practices on more subtle levels. For example, managers influence nursing practices by placing emphasis on supporting clients during specific treatment phases, or whether to invest time in travelling for face-to-face consultations. One *Private Hospital RBN* described how she was not directly told how many hours to work, but encouraged to direct minimal hours to RBN duties since it was an 'add on' role.

RBN employment parameters, such as the hours and essential resources allocated to the role, undoubtedly influence nursing practices. The RBN hours per site varied considerably (6.2 to 30.6 hours), as did the amount of time available per client. Clearly, the number of hours allotted for an RBN to undertake her work impacts the interventions she is able to provide, including the duration of the service. For example, the *Private Hospital RBN Site* had 6.2 nursing hours per consulting client, whereas the *Public/Private Hospital RBN* and the *Community RBN Site* had 11.3 and 12.9 hours respectively. This suggests that the *Private Hospital RBN Site* had significantly less time available to spend with each client as compared to the other sites.

As was identified by RBNs in this study and reiterated in the literature, breast nursing practices are limited by the hours allocated to the role (Victorian Centre for Nursing Practice Research, 2001; White & Wilkes, 1999b). For example, inadequate hour allocation to breast nursing roles was identified as negatively impacting intervention duration, specifically limiting contact during adjuvant treatment and follow-up (Victorian Centre for Nursing Practice Research, 2001). Time constraints have also been identified as an inherent challenge to similar supportive care roles (Howitt, 2010).

Furthermore, RBNs in this study highlighted resources that were enabling for RBNs. Essential resources included private consultation space(s), a regular contact number to receive messages and make calls, as well as access to a vehicle. The *Public/Private Hospital RBN* had an office with telephone and storage space for resources which she worked from her full-time (although undertaking another role a portion of that time). This allowed the *Public/Private Hospital RBN* to maintain a constant presence – and gave a stable location for clients to meet or contact her. *Private Hospital RBNs* expressed concern over the lack of appropriate consultation space(s). Significantly, one *Private Hospital RBN* felt she did not have any appropriate consultation spaces. By contrast, the *Community RBNs* had a centralised telephone line to receive referrals and contacts, as well as vehicles available for booking to travel to clients.

Similarly, the literature points to ‘essential pathways and resources’ in order for clinical care coordinators to be effective, including appropriate means and resources for communication, and opportunities for face-to-face and telephone contact (Howitt, 2010). Other studies have also identified resource issues as performance barriers for supportive care roles (Farber, et al., 2002). RBNs in this study highlighted that wards were unconducive environments for providing supportive care, as has been noted elsewhere (Mohan, et al., 2005). The provision of a private and accessible meeting space demonstrates a clear understanding of breast nursing practices and a greater commitment to bringing about positive supportive care outcomes for women whilst appropriately supporting nurses.

Clinical supervision and support of BNs, although vital, is profoundly lacking in rural practice. This study found the RBNs perceived they did not receive clinical supervision and support in a formal way from their employing organisations. Instead, RBNs relied on peer support for debriefing and reflection on practice. So, although ongoing access to psychological supervision has been recommended for SBNs (SBN Project Team, 2000), none was evident in practice in Tasmania.



Unfortunately, this finding is not surprising. Clinical supervision has not been widely adopted in Australia outside of the mental health nursing area (Mills, et al., 2005). The urgent need for support for oncology nurses attempting to provide psychosocial support has been highlighted in the literature (Watts, et al., 2010). Yet, the lack of access to clinical supervision for BNs has been reported previously in Australia (Victorian Centre for Nursing Practice Research, 2001). Furthermore, the lack of clinical supervision is commonplace internationally – as reflected in a survey of UK breast nurses where 40% reported inadequate supervision, and 60% without access to specialised mental health professionals for supervision (Royal College of Nursing, 2004). Importantly, the lack of supervision and support for RBNs has implications for emotional exhaustion and burnout (Kenny et al., 2007; Yasko, 1983).

Furthermore, as the lack of rural clinical supervision and support is common (Mills, et al., 2010), new strategies to address clinical supervision and support need to be identified. For example, online communities of practice may well prove effective in supporting RBNs across wide regional areas. Therefore, as clinical supervision is undertaken in the work context, employing organisations must identify ways to enable clinical supervision for RBNs to support and improve clinical practice (Mills, et al., 2005).

Indeed, the ability to debrief and discuss difficult cases is essential for BNs. Peer support, from RBNs in the wider healthcare system, was the primary means by which RBNs in this study perceived they received support, and a state-wide breast nurse network provided an important means to enable these interactions. The NBCC Demonstration SBN Project also identified the importance of peer support for BNs (SBN Project Team 2000). Thus, peer support should be supported by employing organisations, as peer support can be especially important in the context of minimal or no clinical supervision and support.

### 9.1.2.2. Health System Support

Not only is support from within the employing organisation essential, but wider health system support is also critical. It is important that RBNs receive support from others within the wider healthcare system in order to provide supportive care to women with breast cancer. Specifically, this study demonstrated that support from the broader health system was influential in shaping rural breast nursing practices. Health system support of RBNs was evidenced in referrals (especially those that were early), and the ability to move freely across institutional boundaries to support women and access information about possible clients in order to make contact. Importantly, support can be formalised into practice (e.g. making RBN referral part of the regular routine/protocol) and support can also be on an informal level (e.g. allowing the RBN to use a spare room for consultation when needed).

Referrals to the RBN are an important means for other providers and services to demonstrate support for, and belief in, RBNs and their services. Furthermore, referrals are a vital means of initiating contact between RBNs and women, and importantly are influential in the timing of the first contact for RBN interventions. One *Private Hospital RBN* in this study described receiving referrals directly from the surgeon's office after the client's first consultation. This demonstrated significant support for, and appreciation of, the RBN and her ability to support women. However, other RBN sites described quite varied referrals patterns from different specialists and services. Importantly, first contact was also initiated by RBNs actively sourcing potential clients (i.e. 'client finding'), from surgical lists, for instance.

Consistent with the findings of this study, the literature points to variability in the first contact point, as well as a need to improve the initial referrals to breast nursing services (Carnwell & Baker, 2003b; White & Wilkes, 1999b). Specifically, surgical services are an important and common referral source for breast nursing services (Victorian Centre for Nursing Practice Research, 2001). Therefore, routine referrals

from key services such as diagnostic centres and surgical wards have the potential to greatly enable RBNs to support women early in their breast cancer journey. Yet, caution should be taken to not exclusively rely on referrals from surgical services, as treatment routines can vary widely.

In this study, RBNs also experienced support from the wider health system in their ability to work across organisational boundaries. The UK government recognises the need for health professionals and teams to work across organisational boundaries (Department of Health, 2000). Yet, in this study inter-organisational issues sometimes prevented RBNs from working across the multiple sites and organisations where their clients received care. For example, support was lacking when a *Private Hospital RBN* was denied access to meet with her clients whilst they were at a public institution's treatment ward.

High level support from the wider system is extremely important to enable RBN processes of care to be undertaken to the best of the RBN's ability. Yet, interpersonal and inter-organisational politics played important part in RBNs gaining access to women or not. The levels of support across traditional organisational boundaries, such as public and private, and hospital and community, had a major influence on breast nursing practices. For instance, support was evidenced in this study when a ward manager from another institution allowed a *Community RBN* to access hospital surgical lists to identify possible clients.

This support from across traditional boundaries within the wider health system enabled RBNs to provide support for women across various sites where they received care. This was particularly important for *Private Hospital* and *Community RBN Sites*. Although *Community RBNs* had consultation offices at their formal sites of employment, they worked to creatively partner with other institutions to utilise consultation areas at the sites where women attended for regular physical care (admittedly with varied success). In this way, RBNs hoped to lessen the burden on clients by travelling to them.

Additionally, RBNs in this study highlighted the benefits of practical support from the wider care system. For instance, a non-profit cancer organisation provided information booklets free of charge for RBNs to provide to their clients, as well as the use of digital projectors for presentations. RBNs found this sort of practical support enabling for their nursing services, to broaden their reach and impact of their work. Additionally, the researcher noted that RBNs spirits were buoyed by the sense that a broader network supported their efforts.

The importance of support from the wider healthcare system is a significant finding, since the vast majority of BN intervention studies have limited research to settings with extensive and wide reaching support of BN roles. However, studies in naturalistic settings, like this one, are more consistent with the reality of 'real world' practice. Furthermore, rural areas may be further behind in their acceptance of psychosocial positions such as the RBN. Therefore, the importance of gaining significant support for RBNs (and indeed the RBN as an individual as discussed in the Individual RBNs section) throughout the employing organisation, and across various other organisations and services that share the care of women with breast cancer may be particularly important in rural areas.

#### **9.1.2.3. Proximity**

The physical feature of proximity was prominent enough in this study to warrant its own category within the conceptual framework for breast nurses' practice in rural settings. The proximity of services and clients, that is, their relative location to one another, has a marked impact on breast nursing practices. The service delivery profiles of RBN sites in this study were related to the RBN's location relative to other services. That is to say, the number of RBN consultations, consultation timing (when in the journey), and delivery mode (face-to-face or telephone) were influenced by the location of the RBN service. For instance, in this study impromptu visits were common for the *Public/Private Hospital RBN* whose office was located along the same corridor as the chemotherapy treatment ward.

Two RBN service profiles arose from this data, which reflected the location of RBN services relative to other locations, namely treatment centres and clients' homes. The first service profile, found in hospital-based RBNs, resulted from the RBN services proximity to other cancer services and 'piggy-backing' RBN consultations on other appointments. Consequently, hospital-based RBN sites had more consultations of a shorter duration, where RBNs had quick 'catch-ups' whilst clients were on site, either scheduled or impromptu. Additionally, these RBN services had a greater proportion of consultations peri-operatively, as they were physically located in the same buildings as surgical services.

The second service profile was from the community-based RBN site which generally travelled to connect with clients (to treatment centres or homes) and/or had involved telephone consultations. Accordingly, the *Community RBN Site* had fewer consultations of a longer duration, regardless of whether consultations were over the telephone or face-to-face. Additionally, as the *Community RBN Site* was neither organisationally nor physically connected to the diagnostic or surgical time periods, consultations were more frequent post-operatively. Importantly, these RBNs discussed many challenges to obtaining referrals earlier in their clients' cancer trajectories.

As was the case in this study, Sidani and Braden's (1998) conceptual intervention framework also highlights how the physical layout of services impacts access and convenience for clients. Undoubtedly, the location of RBN services in relation to other cancer services influences nursing practices. Furthermore, the proximity of RBN services relates to their physical accessibility (as is discussed further in the Availability and Accessibility section of this chapter). RBN services being located at treatment sites, or nearby, made face-to-face consultations more convenient. Contact was more frequent, whether initiated by RBN or client (i.e. drop-ins), presumably because the RBN service was easier to access. Additionally, the literature highlights that as supportive services are integrated within the treatment

plans physically, there is a perception from staff and clients that supportive care is regular part of the journey (Sellers, 2000, p.19).

Indeed, co-location of services has been recommended in the literature to assist the sharing of care through improved communication and coordination, especially in rural healthcare settings (Woodhouse, 2009). Yet, within the literature, the location of the BN within surgical units was seen as a cause of infrequent contact during adjuvant treatment and follow-up (Victorian Centre for Nursing Practice Research, 2001). Therefore, the physical placement of RBN services amongst other cancer care services should be considered carefully as context-dependent nursing practices result, as they have with other supportive cancer care roles (such as the Patient Navigator) (Pedersen & Hack, 2010).

Inevitably, healthcare and other public infrastructures “influence healthcare delivery systems and services in those regions” (Bushy, 2002, p.104). Certainly, there are policy and practice implications emerging from these findings. Namely, “structural factors such as the availability and configuration of healthcare resources, transportation to them, and distance must be addressed when determining the best array of health services for rural clients” (Dunkin, 2000, p.61). Furthermore, it is likely that within the rural context of breast nursing, the distance features become more pronounced, particularly as rural practice is inherently characterised by greater distances between services and providers (Bushy, 2002).

#### **9.1.2.4. Other Services**

Finally, the availability of other services influences rural breast nursing practices, and the experiences and outcomes of clients. Clearly, when services are available, women are able to take advantage of what they can provide. Importantly, the availability of services impacts nursing practices in two ways – referrals from the RBN to other services as well as the scope of nursing practices as the nurse attempts to ‘fill the gap(s)’.

Obviously, women with breast cancer can access professional and volunteer services through referral from RBNs or other health professionals, and/or often directly, only when these services are available. Relevant services include both professional and volunteer services, most notably mental health professionals (e.g. psychologists and social workers) and volunteer support services (e.g. cancer connect and breast cancer support services). Also highly relevant are services that support the physical and practical aspects of life, such as physiotherapists, home help, and transport for treatment services.

The make-up of the healthcare team which women may consult can vary greatly in different areas. Furthermore, it cannot be assumed BNs have formal multidisciplinary teams in which to work, especially in rural areas. For example, in Australian rural hospitals administering chemotherapy, only 43% held multidisciplinary clinics (COSA, 2006). When no multi-disciplinary team exists, as was the case in this study, RBNs may provide an especially important role to 'link' to other services, and 'provide a pivot point' for women (as described in Chapter Seven).

When services are not available to refer women to, RBNs modify their services to attempt to accommodate those needs for especially challenged clients. RBNs described this as 'filling the gap' (as detailed in Chapter Seven). While RBNs felt it was important to stick to their remit, they consciously chose to overstep their bounds to assist clients when no relevant services were available for referral, as in the example where one RBN described assisting a client with a young child who was leaving her partner to become re-housed. Although the RBN perceived this work as 'beyond her brief', she felt obliged to assist as the partnership breakup was perceived as a consequence of the cancer experience. Thus, RBNs felt they needed to expand their scope of practice in order to fulfil their clients' needs when services to support these needs were not available to their clients. Significantly, nurse-led supportive cancer care has also been described elsewhere as being shaped to

address “gaps in support provided by existing services” (Howell, et al., 2008, p.1348).

This adjustment by cancer nurse specialists to the local demands of nursing services has been echoed in the literature, as have the resulting variations in nursing practices (Ream, et al., 2009). Furthermore, internationally rural nurses tend to interface with other disciplines and in fact overlap with other disciplines (Bushy, 2002). This ‘role diffusion’, resulting from fewer healthcare roles providing care in rural areas, is a consistent and well supported theme in the rural nursing literature (Lee & McDonagh, 2010). “In a healthcare context where specialised supportive care services (e.g. help from dietitians, psychologists, social workers) are often unavailable or difficult to access, supportive care remains largely a responsibility of medical and nursing professionals” (Gray, et al., 2002, p.647). Discipline overlap logically leads to an expanded role of rural Australian nursing practices, or role diffusion, which has been highlighted in the literature (Hegney, 2000).

The expanded scope of RBNs, and their hesitancy yet presumed necessity to work in diffuse ways is mirrored in the following quote from the rural nursing literature:

"Rural nurses are understandably reluctant to admit that they practice medicine, but they know their boundaries are sometimes stretched by circumstance. ... Rural nurses consistently and necessarily practice well within the realm of other health care disciplines... . It is a grey area that hinges on circumstances and relationships... . Some nurses embrace this intersection more willingly than others, but none do it casually" (Scharff, 2010, p.260,265-266).

Importantly, access to mental health services is particularly important to comprehensive breast cancer care, but is often absent in Australian and other rural areas (SBN Project Team, 2000; Bettencourt, et al., 2007; Lawler et al., 2010). For example, in Australian rural hospitals administering chemotherapy, only 39% had dedicated oncology counselling services available (COSA, 2006). Indeed, limited



access to mental health services was inherent within this study as well. For instance, only one region had access to a publicly funded psychologist for cancer support. Thus, the lack of psychological and counselling services in rural areas places extra pressure on RBNs who are burdened to 'fill the gap' left by missing services. Importantly, the literature suggests client workloads should be lessened if other relevant support care services are not available for cancer support nurses to refer clients (McIllmurray et al., 1998).

In summary, the distinct context influences the nursing practices resulting in context-dependant services. Breast nursing practices are influenced by the organisational employment parameters such as allocated hours, and the provision of essential resources as well as clinical supervision and support along with more subtle pressures. The wider health system hinders and/or supports the RBN service through early referrals, and freedom of movement and sharing information between traditional organisational boundaries. The proximity of RBN services to other services and their clients influence their service delivery profiles. The availability of other services impacts RBNs referrals as well as their consultation practices in their efforts to 'fill the gaps'.

### **9.1.3. Women with Breast Cancer**

Each woman's individual characteristics shape their needs and responses to RBN care. Importantly, women's needs change through time as her health circumstances change. Women's needs in turn shape breast nursing practices, and women's supportive care outcomes. Although little emphasis was placed on women's impact on the nursing practices within this study, the findings were consistent with that published in the wider literature.

Significantly, Sidani and Braden (1998) identified:

"First, client characteristics may influence the nature, course, and manifestations of the presenting problem and therefore the selection

and design of interventions. Second, client characteristics can influence the clients' response to the intervention." (Sidani & Braden, 1998, p.67)

Accordingly, the Sidani and Braden conceptual intervention framework (1998) identified three categories of client characteristics - personal, illness and/or health, and resources available to clients - as most likely to influence interventions and outcomes. Yet, their categories and lists of client characteristics were "preliminary rather than comprehensive or exhaustive", and "not prescriptive or definitive" (Sidani & Braden, 1998, p.66).

Similarly, this conceptual framework for breast nurse practice is not exhaustive in its description of client characteristics which influence nursing practices and women's outcomes. Instead, this conceptual framework supports the consideration of client characteristics in shaping nursing practices and supportive care outcomes for women with breast cancer. The categories of client characteristics which emerged from these findings were: disease and treatment characteristics, and health status; social, physical, and financial circumstances; and the woman's approach, personality, and preferences.

#### **9.1.3.1. Disease and Treatment Characteristics, and Health Status**

RBNs in this study identified women's disease and treatment profiles as well as their health status impacting their cancer journey, RBN care, and supportive care outcomes. An RBN in this study explained that clients with advanced disease required more assistance from RBNs.

Naturally, the disease status impacts a woman's cancer treatment options and her survival. Hence, a woman's disease status impacts her needs for information and support around treatments, decision-making, and survival, and thus how an RBN works to meet these needs.

The cancer treatments a woman receives impacts her potential and actual symptom burden, and consequently the processes of RBN care. Each treatment regime,

whether surgery, radiotherapy, chemotherapy, or hormone therapy, have their own set of issues to prepare for, and possible side effects to contend. For example, RBNs in this study described preparing and assisting women with different symptom burdens depending on their treatment(s), such as skin burns with radiotherapy and nausea with chemotherapy.

Furthermore, different issues are important and relevant to women at various points in the cancer journey. In this study, different unmet needs were identified across the breast cancer treatment trajectory which likely reflected the predominant issues during that time period. For example, while unmet psychological and information needs were the major issues at one-month post-diagnosis for women, fatigue and physical and daily living issues were more predominant at three-months post-diagnosis. RBNs similarly described the changing issues for women, and how they tailored their nursing to those needs. Therefore, the nursing practices of RBN services will undoubtedly differ as they reflect the predominant issues of the period(s) within the illness trajectory in which RBNs typically support women.

Certainly the wider literature points to the implications of women's disease and treatment characteristics on nursing practices. For instance, unmet needs for cancer patients are typically higher when patients are receiving chemotherapy (Girgis, et al., 2000; Gray, et al., 2002), as well as when the cancer has not stopped growing (Sanson-Fisher, et al., 2000). Furthermore, the disease status and treatments received logically impact outcomes for women as well (Li et al., 2003; White et al., 2004).

Additionally, women's underlying health status can complicate and exacerbate the cancer journey, consequently requiring more assistance from RBNs and health professionals. The woman's overall health status before and during treatment impacts how cancer and its treatment will affect her, and to what extent. For example, women may face co-morbidities such as diabetes which can complicate

treatment plans. In this study one RBN explained how complicated treatment plans demand more attention from RBNs and other health professionals.

Therefore, it naturally follows that RBNs modify their nursing practices to pre-empt and address the issues that are most relevant to their clients' disease, treatment, and health characteristics. Naturally this implies that health services – meaning, employing organisations and RBNs - must prepare to encounter and address the types of issues that will be relevant for their clientele.

#### **9.1.3.2. Social, Physical, and Financial Circumstances**

A woman's social, physical, and financial circumstances, including her socio-demographic characteristics, influence her cancer experience. They contribute to how, and to what extent, the woman will be challenged by the diagnosis, treatment, and side effects, as well as how she will respond to the RBN's care. The RBNs in this study described social support, familial and professional responsibilities, insurance / financial status, and proximity to health and support services as influential in their cancer journey. Thus, these factors influenced women's needs, rural breast nursing practices, and women's supportive care outcomes.

The presence of social support, whether through family or friends, can be beneficial in meeting practical and psychosocial needs. On the other hand, cancer's negative impact can be exacerbated by challenging social circumstances (such as difficult marriages described by RBNs in this study). RBNs described providing more or less support, depending on what other support networks women had. RBNs also assisted women to address the challenging situations that arose in prominence as a result of the cancer diagnosis. For example, RBNs explained strained marital relationships were sometimes pushed to breaking point with cancer diagnosis and treatment.

The importance of social support has been echoed in the literature. For example, socially isolated women are at an increased risk of declined physical function after breast cancer (Michael et al., 2000). Yet, social connectedness promotes resilience in rural communities and individuals (Wainer & Chesters, 2000), and social support has even predicted survival in acute myeloid leukaemia patients (Pinquart et al., 2007).

Women's familial and professional responsibilities impacted their cancer experiences, particularly when they were unable to set these responsibilities aside. RBN explained that if women had many roles and responsibilities, managing these whilst receiving treatment and experiencing side effects often became very difficult. For example, RBNs described their clients being primary caregivers for young children or partners, and raising vital funds for a family's subsistence. There were seen as important jobs which could not easily be put aside to redirect energy and time to combat cancer. In this study, RBNs described attempting to assist women to identify and resolve these issues while holistically supporting woman in their journey with breast cancer. Yet, at times, the weight of women's responsibilities meant they could not make the time to consult with RBNs.

Indeed the multitude of responsibilities for Australian rural women with breast cancer has been noted in the literature, along with women's concerns and worries about them (McGrath, et al., 1999). Furthermore, the literature highlights the need for cancer support nurses to take into consideration all aspects of rural cancer patient's lives (Wilkes & White, 2005). Consistent with the wider literature, RBNs described the nature of rural women's multiple roles at home and at work impacting her ability to use time, money, and effort to look after her own health needs (Winters, et al., 2006).

Women's financial strain often compounded the cancer burden. As described earlier, RBNs recounted that some clients were unable to take time away from jobs to recover from the breast cancer treatment and side effects due to financial pressures. One RBN in this study described how clients with "complicated lives"

required more assistance from the RBN. Furthermore, the literature points to the need to travel for treatment adding to financial burdens and distress for rural Australian cancer patients (McGrath, et al., 1999; Wilkes et al., 2006).

Women's proximity to health and support services shaped clients use of RBN care, as well as how the RBN provided support. RBNs in this study described supporting more rural clients via the telephone rather than the client/RBN travelling to one another. Thus clients who were more rurally based likely had less face-to-face time with RBNs. Similarly, the literature points to different care patterns for rural women with breast cancer (Bettencourt, et al., 2007; SBN Project Team 2000).

Generally speaking, the socio-demographic variables of an RBN service's catchment area shape the needs profile of their clientele. Consequently this influences breast nursing efforts to meet these needs. For example, *Private Hospital RBNs* expressed how their clients, being privately insured, differed from those clients within the public system. Yet, this study did not specifically emphasise nor explore the socio-demographic variables.

However, the literature highlights demographic groups which tend to report higher needs, seek supportive care, and/or are more likely to have psychological distress. For example women with breast cancer who are younger in age, and a parent, report more needs (Griesser et al., 2010). Furthermore, unmet needs for cancer patients are typically higher when clients are:

- younger (ranging from approximately 30-60 yrs) (Carlson, et al., 2004; Girgis, et al., 2000; Gray, et al., 2002; Sanson-Fisher, et al., 2000; Soothill, et al., 2004; Soothill, et al., 2001; Thewes et al., 2004b),
- female (Carlson, et al., 2004; Ernstmann et al., 2009; Sanson-Fisher, et al., 2000; Soothill, et al., 2004)<sup>55</sup>,
- more highly educated (Davis et al., 2004; Gray, et al., 2002),

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<sup>55</sup> However, others have not found gender to be significant (Soothill et al 2001; Zabora 2001).

- holding additional health insurance (Gray, et al., 2002),
- without a religious faith (McIllmurray et al., 2003; Soothill, et al., 2001),
- an ethnic minority (Carlson, et al., 2004; Zabora, et al., 2001), and
- of a higher socioeconomic status (Girgis, et al., 2000; Gray, et al., 2002; Soothill, et al., 2004)<sup>56</sup>.

This implies RBN service planners should be aware of the influence of socio-demographic variables on their clientele's needs, and responsive breast nursing care.

Therefore, RBNs tailor their care to reflect the relevant issues for each woman given her individual social, financial, and physical circumstances. RBNs in this study described being particularly conscious of the influences of social support, familial and professional responsibilities, financial circumstances, and the rurality of the woman's home. Additionally, the literature points to socio-demographic characteristics which tend to report greater needs. In summary, RBNs were cognisant of, and adapted their care to, the many influences in the client's life which impacted her needs and cancer experiences (Wilkes & White, 2005).

### **9.1.3.3. Approach, Personality, and Preferences**

A woman's own approach and preferences impact how she experiences and confronts cancer's physical and psychological impacts, along with shaping the RBN care and cancer treatment she receives. A woman's approach to life more generally, was seen by RBNs in this study to shape her reaction and interaction with the cancer experience. In particular, RBNs explained how each woman brings to the cancer journey coping strategies she has used in the past. Additionally, RBNs described how client's individual strength and resilience could support them in their

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<sup>56</sup> Yet, those with lower socio economic status often are most in need of support and improved care (Aldrich et al., 2003).

cancer journey. When women were 'strong', RBNs noted they did not need as much RBN support as those who lacked effective coping strategies.

Furthermore, a woman's personality traits impacted her desire for assistance, as well as her willingness to share her concerns or raise issues with RBNs and others. For example, RBNs in this study found it challenging to discuss sexuality issues with women who were private by nature. Thus, even if a woman was having an issue that the RBN could have helped her to address, the women's private nature meant she did not present the issue, and also may block RBNs attempts to raise such issues. One RBN explained she could not help women who did not want to be supported.

Women's preferences for their involvement in treatment decisions, as well as their information preferences shaped the RBN care they received. The extent of a client's desired involvement in treatment decisions shaped nursing practices to assist her with these decisions. When women were offered treatment choice and/or when women chose to be involved, RBNs supported their clients' decision-making (as described in Chapter Seven)

Breast nursing practices were also driven by their clients' information preferences. For example, RBNs often described asking women to direct what information they wanted from them. RBNs in this study asked women to tell them when they wanted more or less information about different aspects of their breast cancer journey. In this way, client preferences influenced the information that was distributed by RBNs and the issues discussed in RBN consultations.

Furthermore, client preferences often guided cancer treatments, which in turn influenced breast nursing practices. In one instance, a *Private Hospital RBN* described a client requesting she no longer receive any treatment for her cancer, contrary to the advice of her treatment team. The RBN explained how she supported and assisted the client to convey this information to the specialists



involved. These choices, driven by the woman's own approach and preferences, ultimately shaped the nursing practices, and the woman's outcomes.

Similarly, the generic nursing conceptual intervention framework identified personality traits, beliefs, and values as impacting nursing interventions and client outcomes (Sidani & Braden, 1998). Furthermore, the movement towards involving and engaging cancer patients in their own care, including treatment decision making (Jefford & Tattersall, 2002; Kravitz & Melnikow, 2001), will inevitably result in variations in nursing practices based on client group characteristics, approaches, and preferences.

#### **9.1.4. Rural Breast Nursing Practices**

In this study the clientele, distinct context of care, and individual RBNs influenced breast nursing practices, and variations led to differences in nursing practices. The characteristics of clients, RBN, and context combine to influence how the RBN utilises time overall, as well as in consultations. The delivery, dose, and content of consultations are influenced by the woman, the RBN, and the local context. These factors impact what was addressed and emphasised, what referrals and resources were provided, the delivery mode, and the extent and duration of the RBN service. Furthermore, what is done with their overall use of RBN time is shaped by the clientele, the RBN, and distinct context.

Variations in breast nursing practices were anticipated and indeed found in this study (see Chapter Six). Importantly, questions of the integrity or consistency of breast nursing practices is not applicable, since the RBN works to appropriately modify her care for each individual woman's needs. That is to say, breast nursing practices will differ based on the client's preferences, circumstances, and disease and treatment characteristics. However, as this conceptual framework demonstrates, breast nursing practices also differ based on individual RBNs and discrete contexts.

Sidani and Braden's (1998) generic nursing conceptual intervention framework suggests considering the intervention on micro and macro levels. Micro levels include working directly with patients and/or their families while macro level work is with other healthcare providers or targeting the healthcare system at large. Similarly, this conceptual framework demonstrates how RBNs interface with clients, healthcare providers, and other contextual elements to determine breast nursing practices. Thus, this conceptual framework acknowledges the necessary micro and macro work of the RBN. The micro work is characterised as the consultations with women, while the micro and macro work is encapsulated within overall practice. Consultations and overall practice were described in this study with both quantitative and qualitative strands.

Sidani and Braden (1998) also noted how nursing interventions can be presented including the types of activities and the strength. Furthermore, other literature indicates the importance of clarifying the nursing dose administered (Manojlovich & Sidani, 2008; Stanton, 2005; Whittemore & Grey, 2002)<sup>57</sup>. Similarly, this conceptual framework for rural breast nurse practice describes consultations as per their delivery (i.e. initiation and mode), dose (i.e. timing, number, and duration), and content (i.e. emphasis, and resources and referrals). Additionally, qualitative elements provided 'colour commentary' on how and why nursing practices were done as they were.

The elements of nursing practices which are influenced by women, the RBN, and the distinct context are discussed below. RBN work is considered in two ways; their work directly with clients within consultations (micro), and RBNs overall practices

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<sup>57</sup> Nurse dose has been conceptualised as the purity, amount, frequency, and duration of nursing care (Manojlovich & Sidani, 2008). Stanton et al (2005) highlighted that it is important to know the "number of sessions attended, total contact time, and primary content of the individually tailored intervention" (Stanton, 2005). The strength and timing of nursing interventions are important to understanding client's responses (Whittemore & Grey, 2002).

(micro and macro). Additionally, similarities and differences between rural and what has been reported previously from traditionally urban breast nursing are highlighted.

#### **9.1.4.1. Consultations**

Breast nursing practices directly with women are influenced by the women, RBNs, and contexts. This finding emerged from the integration of the results from Chapters Six, Seven and Eight. RBN consultations are influenced in their delivery, dose, and content.

##### **9.1.4.1.1. *Delivery***

The consultation delivery elements which are influenced include who initiates consultations (i.e. initiation), and whether consultations are held face-to-face or over the telephone (i.e. mode). For instance, if an RBN office is in close proximity to treatment wards then clients can easily initiate impromptu consultations when they are on site (i.e. the influence of context). The likelihood of this happening is enhanced when women are comfortable asking for assistance (i.e. the influence of women), and when an RBN has invited this sort of contact in a way that makes the woman feel at ease doing so (i.e. the influence of RBN). This exemplifies how the context, woman, and RBN all have a part to play influencing consultations (in this case, client-initiated consultations).

The use of telephone support as a delivery mode is more common in rural than urban breast nursing practices. There was a greater proportion of support time provided over the telephone by RBNs in this study than that demonstrated by SBNs in the NBCC Demonstration Project (29% as compared to 17%). RBNs in this study used telephone support as a practical means to enable contact. Similarly, rural clients have previously been identified as less likely to receive face-to-face consultations (SBN Project Team 2000; Victorian Centre for Nursing Practice Research, 2001), and more likely using telephone contacts (Eley, et al., 2008). The

SBN Demonstration Project also highlighted to use of telephone support to maintain follow-up contact with rurally based clients (SBN Project Team 2000). Thus, in an effort to counter more remote clients being consulted with less frequently (Chenoweth, 2004), RBNs utilise telephone support as a delivery mode when necessary.

#### 9.1.4.1.2. *Dose*

The extent and duration of an RBN service, or the 'dose', is influenced by the woman, RBN, and context. Specifically, the dose includes when the consultations happen (i.e. timing), the number (i.e. quantity), and length of consultations (i.e. duration). For example, early referrals to the RBN service (from a supportive context) enable consultations during earlier phases, such as pre-operatively. Also, organisational support in the shape of sufficient RBN hours and valuing follow-up can enable RBN consultations to extend through follow-up phases. Furthermore, a client's treatment journey shapes her needs, and thus RBNs attempt to schedule consultations to reflect each woman's journey whilst anticipating her needs.

The 'real world' presents several dose challenges for RBNs, and many BNs too. Consistent themes in this study and the literature are challenges in early referrals, contact gaps in the woman's journey, and the rigidity/flexibility of care plans. These in turn impact the timing, number, and duration of BN consultations.

Both rural and metropolitan BNs identify challenges in receiving early referrals (i.e. diagnosis and pre-surgical). RBNs in this study highlighted many obstacles to obtaining referrals early enough to enable pre-operative consultations. Consequently, only 17% of women received diagnosis phase consultations. Similarly, only half of a rural Queensland BCN's clients received consultations at or around diagnosis due to delayed referrals (Eley, et al., 2008). The SBN Demonstration Project also highlighted challenges of receiving referrals that enabled diagnostic and pre-surgical consultations, with 63% of clients receiving diagnosis phase consultations (SBN Project Team 2000). Yet, RBNs may find acting

on referrals more challenging than urban BNs due to contextual barriers (e.g. distances) and inhibitive employment parameters (e.g. part-time roles). Thus, the dose of RBN care, particularly the initiation of first contact, is impacted by contextual features.

Similarly, 'real world' BN and RBN services across sites have highlighted contact gaps in the continuum of care. This is despite the role's general aim to support women across their journey. Interestingly, the researcher was unable to identify within the literature a fully comprehensive naturalistic BN service which extends across the full continuum of care. Whereas earlier naturalistic assessments of when BNs were consulting with clients pointed to gaps in follow-up care (Victorian Centre for Nursing Practice Research, 2001), the RBNs in this study identified longer term follow-up and early contact as gaps. Indeed, different services have different challenges based on contextual features. Thus, the employing organisation and employment parameters have substantial influences over the dose of RBN care delivered, particularly the timing and duration of contact.

Although this study revolved around rural practice, much applies to more general breast nursing as well. Specifically, the employing organisations influence on nursing practices. Reports historically point to Australian breast nursing's emphasis on diagnosis and surgical time points, with a neglect of follow-up phases (Campbell, et al., 2006; Victorian Centre for Nursing Practice Research, 2001). A review of typical Australian employing organisations may very well reflect this emphasis, for example BNs being employed by diagnostic centres or based on surgical wards or surgeons' consulting rooms. The Australian emphasis to date has certainly been on the hospital-based phases. As breast cancer care, and healthcare more generally, is shifting to a greater provision of care in community settings and shorter hospital periods, the 'ideal location' for BNs may require some re-consideration.

It is highly likely that naturalistic (i.e. 'real world') breast nursing has more varied care pathways than prescribed clinical pathways. In this study, RBNs described being opportunistic and flexible in their care plans whilst journeying with individual

clients. They modified care when it was convenient or needed by clients. In contrast, the '5in12' clinical pathway provided SBNs with a rigid protocol which to follow. Importantly, the protocol assumes clients go through standard care steps. Also, it assumes early referrals to, and wide health system support for, BN services, along with supportive employment parameters to enable early contact within tight timeframes. This study demonstrated that these may be unrealistic assumptions to make about the breast cancer care systems in rural Australian practice. Importantly, the NBCC Project report stated: "While the clinical pathway establishes a framework for providing continuity of care, it needs to be flexible enough to work within different settings" (SBN Project Team 2000, p.26).

Furthermore, it may be even more important for RBN care pathways to diverge from best practice protocols so as to reflect rural women's needs and wishes. Indeed, women's choices diverging from best practice may better fit within their lives and value systems (Greer et al., 2002). This may be particularly evident in rural women's choices, given the impact of treatment and travel on their and their family's lives. Thus, RBN dose timing likely also reflects women's journeys and needs.

It was interesting to find a similar number of total consultations provided by RBNs and the SBNs within the NBCC Demonstration Project. Although smaller proportions of RBN clients received consultations across various phases as compared the SBN Demonstration Project, the *Summarised RBN* in this study had 4.4 mean consultations per patient. Thus, varied RBN care pathways and a high number of additional consultations provided a similar overall dose. However, the NBCC Project did not quantify the number of additional consultations, so it may be that there was a more divergent numerical dose between SBN and RBN care.

#### *9.1.4.1.3. Content*

The content of consultations is influenced by the woman, the RBN, and the context. The consultation content elements influenced include the emphasis, written

resources and referrals provided by RBNs. Women's needs shape the content, as do the skills and topics that RBNs are most confident and comfortable. Additionally, the consultation space influences what does and does not get discussed. For example, discussing sexuality issues is unlikely in locations that are not private, such as treatment wards. Also, an RBN may not be able to adequately assess a woman's level of distress when she cannot read her body language over the telephone. Furthermore, an RBN can only provide written resources when she has them on hand (e.g. in her office), and only refer clients to the services that exist in the health system to which she has access. Thus, contextual features influence consultation content, as do client characteristics, and RBN's personal and professional characteristics.

Consultation content may vary more widely for RBN services, as opposed to BNs, due to their 'filling the gaps' and complementary work. While it may still occur in urban settings, 'filling the gap' is likely more prominent in rural nursing as there are typically more healthcare roles/services missing from rural healthcare systems. This is consistent with the Cochrane Review's finding that BN work complements that of local healthcare team (Cruickshank, et al., 2008). Additionally, an Australian study highlighted the complementary nature of BN's care to that provided by other health professionals (Halkett, et al., 2006). Indeed, cancer care is a system of care containing a web of interrelated components (Verhoef, et al., 2007). Furthermore, this finding is consistent with rural nursing literature's identification of the diffusion of rural roles (Scharff, 2010).

#### **9.1.4.2. Overall Practice**

How RBNs' distribute their time over a multitude of tasks is shaped by their clientele, the specific RBN, and the distinct context. Most notably, RBNs' travel time, and the proportion of time spent on patient versus non-patient related duties is influenced. However, rural and urban breast nursing practices are consistent in their role's focus of information and support. RBNs in this study described their role

(i.e. overarching aim) in a way that was consistent with the BN role identified in the literature review (Chapter Two). Yet how they go about achieving this aim differs.

The proportion of time RBN sites spend on patient versus non-patient related duties is shaped by their clientele, individual RBNs, and distinct contexts. Employing organisations can directly or indirectly influence RBNs time use, and the wider health system can have similar impacts. For example, the existence of a formal multi-disciplinary team can necessitate BN involvement. Even though rural areas typically do not have multi-disciplinary teams, RBNs still need to communicate with their clients' other providers. It is likely there is a base amount of non-patient related time required to maintain an RBN service, such as professional development, sourcing and replenishing resources, and networking with contacts such as clinicians and 'gatekeepers'. Nonetheless, in this study, a large proportion of overall RBN time was spent on non-patient related duties. This is consistent with the NBCC SBN Demonstration Project (SBN Project Team 2000).

Both urban and rural BNs report significant time required for non-patient-related duties. These proportions were remarkably consistent when comparing the SBN Demonstration Project and the *Summarised RBN*. However, what is done in non-patient related time differs. Although BN activities undertaken in urban and rural contexts are very similar generally (as per Chapter Seven), this study indicates rural breast nursing practices differ in how they go about their role, in subtle but important ways. Specifically, RBNs in this study relied on 'client finding' and played a role in 'filling the gap'. In fact, the need to undertake 'client-finding' activities to identify potential clients was common in this study. The increased RBN involvement in 'filling the gap' was discussed in the previous section.

Furthermore, the services approach to supporting clients influences their overall use of time. For example, BN service provision can be organised in a myriad of ways. For example, in the primarily metropolitan NBCC SBN Demonstration Project, there was a highly scheduled protocol with the vast majority of consultations held face-to-face on site. In contrast, the rural sites in this study provided care



differently and diversely based on the necessity of their context and circumstances. RBNs structured service provision differently, with two patterns emerging in this study. Namely, community-based RBNs travelled to provide face-to-face support resulting in fewer visits of a longer duration, whereas hospital-based RBNs had more but shorter consultations with clients and more often used the telephone support when clients were off-site.

Another issue that differs for rural practice is travel. RBN travel time is shaped by clients' needs, the RBN, and the context. In contrast to BN 'travel' at metropolitan sites (which could be a walk to another building), RBN travel may be over significant distances and therefore demand a greater proportion of RBN time. In this study RBNs travelled to provide consultations at treatment sites (other than their own) and at clients' homes. Additionally, travel was for meetings and professional development. Similarly, the rural health service literature has noted the increased burden on rural services that travel to clients (Asthana, et al., 2003).

Greater distances are inherent to rural nursing, therefore increased travel is anticipated. Indeed, there is increased time spent on travel by RBN sites as compared to their urban counterparts. Travel time took a greater proportion of RBNs time overall as compared to SBNs in the NBCC Demonstration Project (10% as compared to 2%). This time is then not available to provide direct support. Yet, RBNs in this study described being empowered by employing organisations to determine when travel is necessary. However, *Community RBNs* reported they travelled less to support clients in their home as their caseloads increased.

Organisational support for travel is witnessed through the provision of vehicular access, along with managerial support for such travel. Organisations and managers can direct such travel, or be open to an RBN's suggestions for the need to travel. Thus, RBN's interest in, and advocacy for travel for various reasons can impact the site's travel profile, as can the organisation's support for such travel. Furthermore, the distances within the local setting shape the travel times (e.g. between services and clients' homes).

It is therefore not surprising RBN sites report smaller caseloads than primarily metropolitan practices, given increased travel time. This is consistent with other reports of rural practice (Chenoweth, 2004). “Incorporating travel into the regular working day usually means lower client numbers can be served and those in remote areas may be seen less frequently” (Chenoweth, 2004, p.279).

#### **9.1.5. Supportive Care Outcomes**

Characteristics of the client, individual RBN, and distinct context influence rural breast nursing practices and the supportive care outcomes of women<sup>58</sup>. These learnings are drawn primarily from the interview findings, and secondarily the SCNS results of this study and their comparison to similar results. Comparisons put SCNS results into perspective, and serve as a reminder that all unmet needs cannot be entirely alleviated. Although evaluating complex nursing interventions is difficult, the use of a holistic outcome measure appropriately assesses the complimentary support the RBN provides women with breast cancer. The use of multiple measurements was in recognition that supportive care needs change through time. Additionally, the interviews highlighted benefits from RBN involvement beyond individual women, which was consistent with the BN literature.

Similar to this conceptual framework for rural breast nurse practice, Sidani and Braden’s (1998) generic nursing conceptual intervention framework minimises the importance of outcomes in preference for understanding what inputs bring about positive results. “(F)ocusing on the assessment of outcomes alone provides an incomplete and inaccurate picture of the impact of a particular intervention” (Sidani & Braden, 1998, p.10). Instead, it is beneficial to understand how the intervention works, the optimal dose, delivery, and content, and under what conditions favourable outcomes are produced. The features of RBNs, women, and contexts

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<sup>58</sup> SCNS results were characterised as the outcomes as well as an input variable in this study.

emerged in this study as influential in shaping breast nursing and supportive care outcomes.

The literature highlights that the outcomes of complex nursing interventions are difficult to evaluate (Blackwood, 2006). For instance, a challenge to identifying nursing care outcomes are that nursing interventions are often complimentary rather than exclusive to other care providers (i.e. other healthcare professional contribute to outcome as well) (Corner, et al., 2003). Additionally, the variability in approaches to specialist interventions (e.g. working patterns vary significantly) can make outcomes' assessment difficult (Ream, et al., 2009).

Holistic assessments of supportive care outcomes were selected for this study. The use of the SCNS tool placed paramount importance and centrality to the client and their broad supportive care needs. So although a large number of individuals are involved in supporting women which can complicate questions of who is responsible for outcomes, ultimately their actions are meant to be complementary (National Health Priority Action Council, 2006). Thus, as the BN provides supportive care specifically, it is assumed that RBNs adapt their role to fit their clients' needs within their own context. Yet, their aim is ultimately to minimise morbidity due to breast cancer. An analysis of the SCNS results of this study, and their comparison to similar studies, demonstrated the generally favourable outcomes for the women with breast cancer in this study.

Unmet supportive care needs were shown to change over time. Surely needs change as circumstances change, but this has implications for RBN care as well as the assessment of intervention outcomes. Is it appropriate to assess intervention outcomes when the RBN's care is complete? Or are the benefits meant to persist? Disconcertingly, one study found longer time since diagnosis was a predictor of unmet need, however unmet needs at the first time point was the best predictor of unmet needs at the second time point (McDowell, et al., 2010). Yet, questions about the best assessment time as well as the duration of benefits for clients require further research and debate.

Nevertheless, this study illuminated a group of what RBNs perceived as unavoidable feelings, emotions, and cancer experiences for the women with whom they consulted. RBNs clearly conveyed that it is unrealistic to expect RBNs, or any healthcare professional or team, to enable all of women's supportive care needs to be met. This extended the conceptual framework by adding inevitable client experiences and emotions to the characteristics that affect breast nursing practices and outcomes for women.

Nurse's aim to prevent, alleviate, and/or resolve issues for their clients was highlighted by Sidani and Braden (1998). Nurses both pre-empt and address issues with clients, with the insight that some issues may be resolved while others will only be alleviated. This supports the finding that not all supportive care needs can be met, as the RBNs in this study emphasised. One's realm of control over unmet needs is not infinite, that is, there is a limit to the amount BNs or any health professional or person can make the situation better.

Specifically, as cancer remains a life threatening disease and its treatment continues to be physically challenging, it is understood that some issues cannot be fully resolved by RBNs or other health professionals, for example, fears about cancer returning or spreading. Although RBNs can explain how reoccurrence is unlikely given a woman's cancer staging and treatments, there is still a chance that it could return for her as an individual. So although it is highly unlikely, her fears are not without grounding. In essence, women with breast cancer will face inevitable experiences and emotions even under the best possible care.

Significantly, positive outcomes were identified beyond the primary outcome of this study (i.e. unmet supportive care needs). A number of positive flow-on effects of the relatively newly formed RBN positions were highlighted by RBNs in interviews and within the researcher's general correspondence. For instance, the only state health funded psychologist available to cancer patients reported she was receiving appropriate referrals (i.e. fewer referrals overall) resulting in more efficient use of her time (Personal correspondence with Psychologist, 2006). This is consistent with

other studies which reported that the inclusion of cancer support services lightened clinicians load and enabled them to take on more clients (Sellers, 2000; SBN Project Team 2000). Additionally, relevant educational events for general RNs were increased, as was a public presence at annual state-wide events (Ellis, 2006). Similarly, other researchers have identified BNs influence the wider health system to respond more appropriately to women's needs (Amir, et al., 2004).

In summary, this conceptual framework illuminates how the characteristics of the woman, RBN, and context influence breast nursing practices and women's supportive care outcomes. Similarly, the literature highlights that rural nursing practice and rural healthcare systems are inherently relational and contextual (Lauder, et al., 2006). Thus, the features beyond individual women, specifically the RBN and context – including physical environment, organisational support, and key players – have a major influence on rural breast nursing practices.

## 9.2. Availability and Accessibility

The most significant concept impacting the success of RBN services in this study is the availability and accessibility of the RBN, client, and healthcare services. The availability and accessibility concept is a truly cross cutting theme which nests neatly within the conceptual framework described above. It provides greater insights to the importance of the available and accessible features to the success of RBN services. These factors have significant influence on the ability to implement the desired BN interventions, and consequently is an important indicator of 'success'. That is, an RBN service is more likely to bring about positive outcomes for women when available and accessible features are present.

'Available' and 'Accessible' have similar overlapping meanings with slightly different definitions. Available means 'able to be used or obtained; at someone's disposal' (Oxford Dictionaries, 2011b). Accessible means a place that is 'able to be reached or entered' or a person that is 'friendly and easy to talk to; approachable' (Oxford

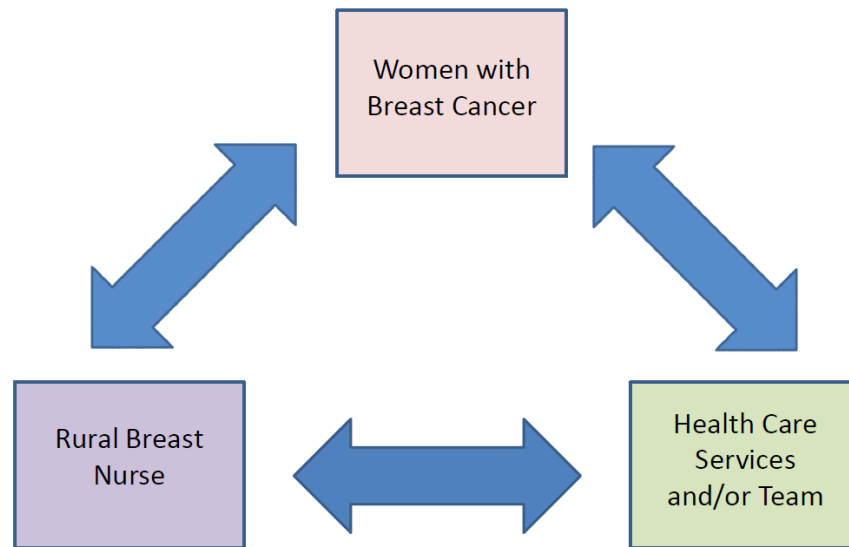
Dictionaries, 2011a). Together, and within the context of this thesis, these words convey convenience, ease, and openness to communication and contact.

Client factors, RBN characteristics, and contextual features all influence the degree of availability and accessibility. Furthermore, they impact breast nursing practices and ultimately the supportive care outcomes for women with breast cancer. The availability and accessibility concept is displayed in Figure 13, and described below in relation to clients, RBNs, and healthcare teams.

Key cross-cutting interrelated features influencing the availability and accessibility of women with breast cancer, RBNs, and healthcare teams and/or services are:

- regular and sufficient allocated RBN hours;
- one RBN service referral point for public and privately insured clients;
- regular contact and collaborative communication between RBN and other healthcare providers;
- timely referrals across services;
- physical proximity and service layout between RBN services and other relevant providers and services;
- wider health system support allowing for RBNs to cross traditional organisational boundaries;
- appropriately located and secluded RBN consultation areas;
- willingness and capacity of clients to utilise RBN services; and
- the approachability of the nurse (for healthcare providers and women).

**Figure 13: Availability and Accessibility Concept for Women with Breast Cancer, Rural Breast Nurse, and Healthcare Services and/or Team**



Essentially, this finding highlights the critical feature of being available and accessible. Clients benefit from being able to access RBNs and healthcare teams, just as breast nursing benefits from the availability to clients and the healthcare team. Similarly, the healthcare team benefits from their ability to access RBNs and clients. When all components are available and accessible to one another, breast nursing practices are more likely to be in line with women's needs, RBNs and healthcare teams are better able to provide coordinated care, and women are more likely to receive positive supportive care outcomes.

### **9.2.1. Availability and Accessibility of RBN to Women**

A key feature of the success of breast nursing services is clients' ease of access (Eley, et al., 2007). Quite possibly the most important feature of BN services repeatedly identified by women in Australia in the scientific literature is the availability of the BN (Eley, et al., 2007; Halkett, et al., 2006). The importance of the availability of the BN to women cannot be understated. The essential requirement of being available has also been highlighted elsewhere, e.g. BN services in North

Wales identified a major area for improvement the need to increase the service's availability (Carnwell & Baker, 2003c).

There are many ways clients benefit from having accessible RBNs. Firstly, the greater RBNs availability, the easier it is for clients to schedule consultations at a convenient time and place. Secondly, when RBNs are accessible, women can – and feel welcome to – initiate contact with RBNs to schedule additional appointments or ask questions when necessary. Finally, when RBNs are accessible on an interpersonal level, women are more likely to bring up sensitive issues such as emotions, relationships, and sexuality.

Features related to the physical context, RBNs interpersonal skills, and individual clients influence how accessible RBNs are to women. A woman's health status, circumstances and personality impact how available the RBN is to her personally. Contextual features such as proximity and employment parameters impact the availability of RBN services to clients. Indeed, travel distances and services layout are important to the availability and accessibility concept.

The RBN's allocated hours also influences how available the position is to clients. The literature identifies that women feel full-time BN positions are accessible (Eley, et al., 2008). A study on the specialist prostate nurse revealed nurses' accessibility to the patient as a key aspect of the specialist nurse role, both in the amount of time they could spend with clients and the availability to be contacted throughout their cancer journey (Tarrant, et al., 2008). Likewise, time constraints are identified as limiting the availability of specialist nurses (Howitt, 2010). Similarly, RBNs in this study identified ad hoc positions as particularly challenging while fractional positions could also limit accessibility.

The RBN's personal nature and education combine to influence both how she interacts with clients to support women to perceive the RBN is available. Available in this case means open to discuss difficult topics, as well as available for client-initiated contact. The literature highlights that patients feel more secure when



health professionals tell them they are available and how to contact them (Williams & Irurita, 2004).

There are many implications arising from these findings. Firstly, it is beneficial to be aware of the limitations that women's circumstances (e.g. rurality, telephone and/or vehicular access, health status) may put on their ability to access RBNs. Secondly, the convenience of client's access to the RBN should be considered when planning the layout and design of RBN services. This may also mean that community-based services should prioritise travelling to consult with clients when circumstances warrant, as was the case in this study. Thirdly, a reasonable allocation of RBN hours promotes client's sense of availability, along with RBNs actual availability. Finally, RBNs should attempt to communicate their availability to clients whilst inviting client-initiated contact.

### **9.2.2. Availability and Accessibility of RBNs for the Healthcare System**

Women's overall care and supportive care outcomes have the potential to benefit when the RBN is available to the healthcare system at large. On the most basic level, when healthcare professionals and services can access RBNs to support their clients, they are able to send referrals to RBN services. By RBNs being available and accessible, health providers can communicate with RBNs to better coordinate the care of their clients. Furthermore, providers might rely on an available RBN to assist with particularly challenging issues for a client. The healthcare system might also benefit by RBNs providing education and training for other providers (e.g. educating nursing staff about specific supportive care issues for women with breast cancer).

Contextual features and RBN characteristics influence the availability of RBNs for the healthcare system. Familiarity with the RBN is important, specifically previous shared experience between RBNs and gatekeepers and specialists. The contextual features of the allocated hours, referral point(s), and proximity all influence RBN availability. These are related to the employing organisation as well as the wider health system. Health providers are able to confidently refer their clients when

RBNs provide regular and consistent availability through a reasonable number of allocated hours.

There are implications for nursing practices arising from these findings. It suggests the perception of RBN availability increases for the healthcare team when the RBN has previous experience with health providers, and works reasonable and consistent hours. Additionally, one RBN referral site regardless of clients' insurance status simplifies the referral process for other providers. Furthermore, regular contact between healthcare providers and RBNs assists in keeping communication channels open. Finally, the location of RBN services should be considered in light of other relevant services and providers.

### **9.2.3. Availability and Accessibility of Clients to the RBN, and the Healthcare System**

Simply speaking, RBNs require access to clients in order to work directly with women to lessen the burden of breast cancer and its treatment. Similarly, the healthcare system cannot benefit a woman without her entering its services, and agreeing to receive its services.

Features which influence the availability of clients to the RBN are related to the context and the client. Women choose to be available to work with RBNs on two levels: choosing to receive RBN supportive care, and being open and willing to discuss sensitive topics or concerns. Of course, both contain continuums of levels of engagement. These decisions are influenced by a woman's personality, health status, and personal circumstances. For example, the availability of women to RBNs is shaped by women's openness to receive different levels of RBN support.

Contextual features also influence the availability of clients to RBNs. These contextual features include organisational and inter-organisational features as well as physical distances, while both physical and socio-cultural issues are relevant. Moreover, BNs access to women occurs at two stages: identifying potential clients, and having ongoing consultations.

At the first stage, RBNs require broad healthcare system support to identify potential clients. Potential clients were identified in two ways in this study: referrals and 'client finding' (as discussed in Chapter Seven). Systems failing to offer referrals to psychosocial services in cancer setting are also reported elsewhere (Curry, et al., 2002). Notably, 'client finding' relies on RBNs' informal networks. Importantly, the first point of contact dictates which treatment phases RBNs are able to assist women through.

During ongoing consultations (i.e. the second stage of availability), clients' availability to RBNs is also influenced by socio-cultural and physical contextual features. Maintaining ongoing contact with clients necessitates consultation location(s), resources to make contact (e.g. telephone and/or vehicle), and support from the employing and other organisations to continue contact. Rural services utilise travel and telephone support to increase the availability of their clients (as discussed in Chapter Six). Yet, while consultation locations and essential resources may be relatively straightforward, organisational and inter-organisation support tends to be more complex.

The socio-cultural features of employing organisations and the wider system have significant influence on the accessibility of clients to RBNs in their efforts to maintain ongoing contact. First of all, the employment conditions and directives shape the dose of interventions RBNs are able to provide clients. In this study, the resources and values of the employing organisation influenced how RBNs went about accessing women. Secondly, the wider health system influences RBNs' ability to continue to access clients. Wider health system support is required to enable RBN mobility across services and sites, allowing RBNs to overcome traditional organisational boundaries (i.e. public/private and hospital/community) to physically access their clients. The RBNs' ability to move across various treatment locations was one of the most valuable attributes of the SBN in the NBCC Demonstration Project (SBN Project Team 2000). Finally, physical distances and proximity shape how RBNs access clients for ongoing consultations. As was the case in this study, the RBNs

proximity to other cancer services enabled more frequent face-to-face contact because of convenience.

Similarly, the healthcare system can only assist women when they enter the system and are willing to pursue health concerns or treatments. Client features influence the availability of the client to the healthcare system. For example, rural women's treatment decisions are frequently influenced by their rural context including social and occupational obligations (Gray, et al., 2004; Greer, et al., 2002).

These findings have implications on improving the availability of clients to RBNs. Firstly, RBNs and health systems must continue to respect the woman's right to decline some or all care. Next, service planners should consider the influence of socio-cultural and physical contextual features on an RBNs ability to access clients in the beginning (i.e. initial referral and contact) and during ongoing consultations. Consultation locations, essential resources, and organisational and wider system support to access clients should be well thought-out. It may be that upon consideration of these contextual features, service planners determine that RBNs will not have appropriate levels of access to clients to enable the service to be successful. In this case, service planners may set about to improve support for RBN services before implementing them.

#### **9.2.4. Availability and Accessibility of Healthcare Services and/or Team to RBNs and Women**

When woman have access to healthcare services, they can then benefit from their use. Also, the client's overall care and its coordination can be improved when health services communicate with each other about their shared clients. More specifically, when healthcare providers are accessible to RBNs, they can exchange relevant information about specific shared cases.

RBNs can request further detail about specific clients when relevant healthcare providers are available and accessible to them. This enabled RBNs in this study to more consistently support and educate their clients, while enhancing care

coordination. Also, RBNs informed clinicians and gatekeepers of relevant issues and clients which they were not aware of (i.e. 'slipped through the cracks').

Physical and socio-cultural contextual features relating to the employing organisation and other relevant health services influence the availability of the healthcare team to the RBN. Socio-cultural components appear to be most important. Although physical contextual features can provide barriers, it seems that mutually supportive working relationships can overcome many of these barriers. Regular contact between healthcare providers and RBNs helps to improve the accessibility of the healthcare team to the RBN.

The BNs ability to liaise between the patient and the medical system has been identified as a key component of specialist cancer nurses (Tarrant, et al., 2008). "...Shared knowledge and free flow of information, communication strategies and linkages between local providers and distant specialists" are significant (Mueller & MacKinney, 2006, p.45). This liaising and communicating indicate RBNs part in enabling continuity of care for women. The literature supports the idea that RBNs contribute to the informational, relational, and management of continuity of care (Haggerty, et al., 2003).

These findings imply that service planners need to consider and enable RBN communication with health providers and vice versa. This generally necessitates the support of employing and other organisations. The communication can be formal or informal, but requires support from relevant health providers. By enabling the exchange of information and ideas about specific clients, as well as learning from one another more generally, client care and coordination can be improved.

In conclusion, availability and accessibility features are significant in influencing RBN services, and their likelihood of success. Characteristics of the woman, RBN, and context combine to influence the availability of different components to one

another. Importantly, availability and accessibility features warrant particular focus and attention when implementing supportive care roles.

It may be that the available/accessible concept is (and can be) taken for granted in metropolitan areas, as these elements are generally fulfilled within these settings. But for rural settings, the importance of the available/accessible concept can direct RBN service design and implementation. As the literature notes, the optimal health service design in rural areas may differ from those of urban areas (Asthana & Halliday, 2004), and many factors must be considered to determine the best way to organise services in rural areas (Dunkin, 2000).

### **9.3. Chapter Conclusion**

This thesis has demonstrated the utility of utilising a pragmatic paradigm along with the intervention conceptual framework to describe and understand rural breast nursing practices. Using this approach, various influences on nursing practices were identified. By taking a health services viewpoint, individual RBN characteristics and distinct contextual features stood out as shaping nursing practices. These were in addition to the previously recognised influence of clients on RBN interventions. These findings, together with the literature, formed the basis of the conceptual framework for rural breast nurses' practice.

Furthermore, the importance of the availability and accessibility concept was identified. The availability of all components – RBN, woman, and healthcare services - to one another is an important indicator of the likely success of RBN services. Therefore, it is wise to consider features of availability and accessibility when planning and/or reviewing RBN services.

Many issues are indeed consistent across rural and urban breast nursing practices. Across all settings credible BN professional identities are important, as is broad healthcare system support. Nonetheless, urban and rural BNs consistently report challenges in obtaining early referrals. Socio-cultural and physical features of

employing organisations influence the consultation timing of BN services. Diverse care pathways and contact gaps appear consistent across urban and rural services. All services report significant amounts of non-patient related time. Additionally, BNs modifying interventions based on clients' disease and treatment status, personal approach, personality and preferences is universal.

Nonetheless, some issues are especially prominent for RBN services in rural contexts. Challenges can exist in identifying candidates with appropriate education, skills, experiences, and personalities that also hold important local knowledge and connections. Informal networks and relationships appear more important and influential for RBNs than for their urban counterparts. Additionally, difficulties have been highlighted for RBNs attaining professional development and especially clinical supervision and support. Thus for RBNs there is an increased reliance on and importance of peer support and learning.

Rural contexts can also influence RBN service availability. Diminished employment hours can negatively impact availability/accessibility to both women and the healthcare team, as can the physical dislocation of and distances between various services. That is, distance features can make RBN services less accessible. Furthermore, challenges in receiving early referrals are exacerbated in rural contexts by greater distances and part-time roles.

Rural nursing practice also differs in a keys ways. Specifically, the literature highlights the greater influence of context on rural practice than for urban practice. RBN services have an expanded scope, including 'client finding' and 'filling the gap' identified in this study. RBNs use telephone support more often as compared to urban BNs. Also, RBN services report increased travel time and smaller caseloads. It may also be that rural breast nursing is more clearly influenced by rural clients' responsibilities related to their multiple roles, yet it is unclear whether this has been considered in urban contexts.

These findings suggest how RBN services should be considered and organised across various rural contexts to maximise positive outcomes for clients. Present, developing, and potential RBN services need to consider their clientele's personal and health circumstances, RBN's personal and professional characteristics, and contextual physical and socio-cultural features to design appropriate services within each context. The next chapter will consider further the implications of the study findings.



# Chapter Ten: Conclusion - The Future of Rural Breast Nursing

This chapter summarises the thesis and provides recommendations for future directions in rural breast nursing. The contributions of this thesis and its significance are highlighted. The results to the research questions are summarised. Additionally, the strengths and limitations of the research approach are discussed. Finally, recommendations are made for the future of rural breast nursing and BN research.

## 10.1. Summary of Thesis

The aim of this pragmatic health services study was *to advance knowledge of rural breast nurses' practice within real world contexts*. This thesis informs effective rural breast nurse practice by investigating the impact of various rural contexts on practice and outcomes while building on previous knowledge of breast nursing care.

This thesis is significant because it applies a general nursing conceptual intervention framework (Sidani & Braden, 1998) to consider the impacts of client, nurse, care, and context on nursing practices in naturalistic rural settings. This thesis developed Sidani and Braden's (1998) generic nursing conceptual intervention framework into a specific conceptual framework for rural breast nurse practice. Within this thesis a diagram was developed for the Sidani and Braden framework, which was then filled and adapted to reflect the findings of this study. More generally, this study fills a gap of oncology health services research in rural areas. Furthermore, it provides a comprehensive description of rural breast nursing practices in Tasmania, Australia. These findings informed an RBN-specific conceptual framework which is useful to guide RBN services, and other rural supportive services.

Several contributions to research were made by this thesis which had been identified as gaps in the Literature Review (Chapter Two). Namely, this study provides significant contribution to literature around *rural* breast nursing practice, which has been scant. It provides a comprehensive and detailed description of real world breast nursing practices. This covers the full care continuum including RBN consultation dose, delivery, and content provided to clients, as well as RBN activities outside of direct client consultations. Thus, this study adds to the limited research describing and informing the structure of breast nursing services, including practical aspects such as telephone support and the use of time. The study also included a comprehensive assessment of systems of cancer care, given that the broad outcome measure assessed RBN care in concert with the full care system. This assessment adds weight to the effectiveness of the RBN services in real world settings, which are complementary to other care providers. Also in this study, considerations were given to how different contextual features shaped rural breast nursing practices. Moreover, this study considered the nurse who embodied the role as impacting nursing practices. Finally, this study provides a conceptual framework of RBN practice to guide RBN care, service development, and improvement in rural and regional areas.

The research process followed a sequential, explanatory mixed method design. Quantitative results about how RBNs used their time more generally and directly in consultations, along with their client's unmet needs over two time points, drove the RBN interview questions and discussions. Together, the findings of quantitative and qualitative strands informed the conceptual framework developed within this thesis.

The questions of this research study were answered in the previous four chapters. The answer to this study's sub-questions and overarching research question are briefly summarised here.

**a) To what extent do women consulting RBNs have their supportive care needs met?**

This question was answered in two ways, assessments of unmet needs were undertaken with the SCNS, and comparisons of these were made with other appropriate samples. These results are reported in Chapter Five.

Assessment of unmet supportive care needs of RBN clients over the first three months of their illness demonstrated the type and extent of high unmet needs. While overall unmet needs decreased over time, unmet needs changed over time. At one month post-diagnosis the most prevalent unmet needs were related to the Psychological domain, yet some items related to the Health System and Information domain. The most prevalent unmet needs at three months post-diagnosis were primarily from the Physical and Daily Living domain, yet Psychological items were also prevalent. Changes in mean domain high unmet needs highlighted statistically significant declines in Psychological and Health System and Information domains, whereas Sexuality domain unmet needs increased slightly. These are shown in Table 12. At the same time, RBN clients' access to services was generally favourable, with the exception of easy parking.

Comparisons to other findings help to put these results in context. When compared to the findings from other cancer and breast cancer samples, the unmet supportive care needs profile of women consulting RBNs in this study was generally favourable. Specifically, women reported fewer high unmet needs in the Psychological and Health System and Information domains. However, some unmet needs persisted for this sample as they have for others, namely fatigue and easy parking. Appropriate comparisons are discussed in Chapter Five. Although many reasons could explain the differences, it seems likely that the support and care of the health system in conjunction with the complimentary work of RBNs made significant contributions to this samples improved status.

**b) What are the nursing practices of RBNs in real world settings, and how do they compare to the primarily urban NBCC SBN Demonstration Project?**

RBN Day Logs, Consultation Logs, and Study Patient Lists were used to answer what RBNs do in practice. Furthermore, comparisons were made with the NBCC SBN Demonstration Project wherever possible to understand similarities and differences between rural and primarily urban breast nursing practices. These results are reported in Chapter Six.

Rural breast nursing practices differed from primarily metropolitan nursing practices in important ways. Specifically, in comparison to the NBCC SBN Demonstration Project, RBNs provided more support via the telephone, and spent a greater proportion of time in travel. Additionally, smaller proportions of RBN clients received consultations during the designated consultation phases. However, the overall distribution of time use by RBNs and SBNs were remarkably similar. Both contributed a considerable amount of time to non-patient related duties. Nonetheless, RBNs spent substantially more time in travel, while SBNs had more time to redirect to patient care after their involvement in the NBCC Demonstration Project.

Yet, extensive diversity was demonstrated across rural breast nursing practices. Interestingly, nursing practices in this sample demonstrated two different approaches to supporting rural clients. The community-based site elected to travel to consult with clients face-to-face thereby providing fewer but longer consultations, whereas the hospital-based sites consulted with clients more often with shorter consultations. Additionally, the gaps in the care continuum were varied for different sites.

**c) How do RBNs describe their nursing practices, and what factors influence their practices?**

Semi-structured interviews with six RBNs answered this question. Chapters Seven and Eight reported RBNs subjective understandings of what they do directly with clients and more generally. Nine distinct processes of RBN care were summarised, namely providing a pivot point, linking, providing information or ‘translating’, dealing with emotions and coping, supporting decision-making, “filling the gap”, advocating, client-finding, and collaborating. These care processes were generally in line with previous descriptions of breast nursing. Yet, both client finding and “filling the gap” were different and/or more pronounced than previously reported.

RBNs highlighted various influences on their nursing practices and clients’ outcomes. These were consistent with the generic nursing conceptual intervention framework provided by Sidani and Braden (1998), and included nurse, client, intervention, and contextual features. RBN influences included professional and personal characteristics, while women’s influences included personal, health, and resource factors. Contextual features influencing outcomes were categorised by physical features including time and space, sites and services, and working conditions, and socio-cultural features including people and services, and employing organisations.

**What factors are important in shaping rural breast nursing practices, and how do these factors exert their influence on breast nursing and the supportive care outcomes of their clients?**

Chapter Nine synthesized the findings from the quantitative and qualitative strands reported upon in the previous results chapters to provide a conceptual framework for breast nurses’ practice in rural settings, and identify the importance of availability and accessibility features of and for RBNs, clients, and the healthcare team.

This study identified many factors which influence rural breast nursing practices. Specifically, socio-cultural and physical contextual features related to employing organisations, healthcare systems, and other relevant services. Also nursing practices are influenced by RBNs' professional and personal characteristics related to education, skills, and contextual knowledge; personal nature and characteristics; and informal networks and familiarity. Furthermore, a delicate diplomacy drives RBN actions, shaped by individual RBNs and members of the loose healthcare team. Additionally, this study identified clients shape breast nursing practices through their disease and treatment characteristics, and health status; social, physical, and financial circumstances; and approach, personality, and preferences.

The features of distinct contexts, individual RBNs, and clients exert their influence on rural breast nursing practices in a myriad of ways. They also directly and indirectly affect women's supportive care outcomes. Significantly, these features can support and/or inhibit best practice interventions for women with breast cancer. Contextual features shape the RBN interventions delivered, such as their timing and the dose. RBN features influence the way each RBN undertakes breast nursing, and how she goes about consultations with clients, for example, the areas RBNs address proactively based on their knowledge, education, and personal confidence. Client features influence consultation dose, delivery, and content. For example, clients may be open to discuss sensitive issues or not, thereby influencing consultation content. Also, clients may take the initiative to contact RBNs when issues arise, and in so doing shape dose.

Significantly, this study identified the importance of available and accessible features as an indicator of likely success for RBN services. The availability and accessibility of RBNs, clients, and healthcare team to one another is integral to their effectiveness. Although it appears RBN services and healthcare systems can be effective in supporting clients without all of these features, they greatly improve the likelihood of RBNs being enabled to support clients effectively.

In conclusion, the study findings demonstrate the importance of contextual and RBN features in shaping rural breast nursing practices. Additionally, the findings support what is known about client features shaping nursing practices. Moreover, the study highlights issues which may be more relevant to non-metropolitan settings. Furthermore, it highlights the importance of the availability and accessibility of women, RBNs, and the healthcare team to one another.

Therefore, by answering the research questions this study has fulfilled the research aim set out at the beginning of the study. A conceptual framework for RBN practice has been proposed - developed from the ideas presented by Sidani and Braden (1998) - based on the features which influence breast nursing practices and clients' supportive care outcomes (presented on page 272). Moreover, it also contributes to rural nursing and rural supportive care theory.

#### **10.1.1. Strengths of Research Approach**

The strengths of this research approach are its practicality and usefulness whilst being imbedded within a pragmatic theoretical and methodological approach and utilising a generic nursing conceptual intervention framework.

Using a conceptual intervention framework to consider nursing practices is relatively new to BN research, as is the focus on rural practice in particular. Focussing on the many factors influencing rural nursing practices sets this study in an applied interdisciplinary health services field. Previous studies have primarily focused on BN interventions and client results, rather than considering the diverse influences on nursing practices. Thus, this study considered rural breast nursing practices - as a subset of breast nursing - in a naturalistic setting with a wider lens of attentiveness.

Furthermore, the pragmatic ontology and resulting methodology provided strength for this study. As neither quantitative nor qualitative methods could adequately address the overarching research question on its own, quantitative and qualitative approaches were combined to best address the research questions, and build upon

one another. Thus, the pragmatic ontology led to the use of mixed methods which naturally increased the scope and comprehensiveness of the findings. The descriptive capacity was strengthened given the mixed methods, and was also able to answer both *what* and *why* research sub-questions.

This research approach led to practical and useful results. This research study arose from the researcher's challenges in finding research to drive effective and sustainable RBN service development. Thus, a practical approach was used to address a real world problem. By taking this approach the study sheds light on the understudied area of rural breast nursing practices and more clearly illustrates challenges for RBN services.

#### **10.1.2. Limitations of Research Approach**

This research approach also has limitations and weaknesses, as any research approach does. It is unlikely that the conceptual framework of RBN practice is fully comprehensive since this study was only undertaken in one state in Australia. Although three different sites were assessed (including seven individual RBNs), other settings might shed light on additional features which influence nursing practices and clients' outcomes. However, as it is a conceptual framework, it can be utilised across various settings to provoke thoughtful insights to service development and improvement. Therefore, the development of a conceptual framework provides a step forward in increasing knowledge of rural breast nursing practices and the influences on it and outcomes. Additionally, it provides a launching pad from which others can test their theories, thereby increasing knowledge further.

This study did not assess the RBN services individually. Instead, this study assessed the effectiveness of the RBN services in concert with other breast cancer care systems. Thus, it is possible that breast cancer care systems set within social framing (of positive views of and support for breast cancer and mental health generally) – rather than the RBN services specifically - were primarily responsible for



the favourable outcomes in this study as compared to previous studies. This cannot be ruled out as an appropriate sample for comparison was not obtained (i.e. from a similar rural setting during the same time period but without the support of a BN). Also, SCNS validity concerns were raised in this thesis i.e. whether participants genuinely understood the scale, even though the SCNS has been validated and is widely used. Indeed, issues arise when attempting to evaluate the effectiveness of individual RBN services.

Firstly, as RBN services are inevitably complementary to other care services (and current social framing), extricating their impacts from one another is challenging. How can a researcher, or a client for that matter, determine exactly which service is responsible for what proportion of their psychosocial outcomes when services are complementary to one another? Furthermore, as women consistently report positively about RBN services in particular, they are not a reliable unbiased source. Thus, any assessments will inevitably capture the effects on women of the combination of RBN services, the wider cancer care systems, as well as the current social framing of breast cancer. Instead, the focus of this study was to assess RBN services as part of a system of care with a holistic outcome measure.

Secondly, RBN services could not be individually evaluated due to confidentiality issues. In many instances RBN quotes could not be directly linked to specific RBN services and/or sites as this would have undermined their anonymity. Nurses' identity needed to be protected in order to enable them to speak freely and honestly about their experiences and insights on rural breast nursing.

Additionally, this study was limited in other ways by the need to maintain RBN confidentiality. Due to the distinct characteristics of the three healthcare contexts and small size of Tasmania, this meant RBN quotes could not be directly linked to their settings so as to protect their identity. While this affected research transparency, the analysis was not inhibited by this confidentiality, and therefore the conceptual framework was built from full access to the data.

## **10.2. Future Directions and Implications**

These findings have implications for researchers, service planners, managers, RBNs, and advocacy groups. By expanding the thinking about BNs to include rural settings, and the many influences on rural breast nursing practices, more thoughtful RBN and BN service development and improvements can result.

As rural breast nursing practices have not been previously described in the literature, these results are valuable for managers attempting to design and implement rural breast nursing services, and possibly shape education curriculum. Furthermore, these results inform managers and program designers to establish services that more adequately reflect rural contexts, with respect for the diversity inherent across various non-metropolitan settings. These findings are constructive for building our understanding of supportive roles caring for people with cancer in rural areas as the results identify areas of similarity and difference from the traditionally described metropolitan or cancer clinic care approaches.

These findings challenge the unstated assumption that BNs can simply be employed, implement effective practice, and consequently bring about positive supportive care outcomes for women in rural areas. This is a clearly a simplistic belief. Instead, recommendations to implement supportive care nursing roles would benefit from more than a cursory reference to the need for wider healthcare support for such roles. Furthermore, the scientific, policy, and nursing practice discourses should reflect the challenges and benefits of distinct setting features and individual BN characteristics. It is likely then that more thoughtful and contextually reflective approaches to breast nursing would result.

There are four broad recommendations emerging from the thesis discussion and implications, followed by specific recommendations for different groups.

### **10.2.1. Recommendations**

Recommendations based on the study findings revolve around acknowledging the many influences on rural breast nursing practices. Specifically, the influences of discrete contexts and individual RBNs on nursing practices and client outcomes must be recognised, considered, and acknowledged. Service development and improvement must acknowledge the potential influences of physical and socio-cultural contextual features, individual RBN characteristics, as well as clients on the resulting rural breast nursing practices. More precisely:

1. Recognise, acknowledge, and respond to the influences that:
  - a. physical and socio-cultural contextual features of discrete contexts have on breast nursing practices and client outcomes. Specifically, consider the features of employing organisations, healthcare systems, other services, and the proximity and layout of services in relation to each other and clients.
  - b. RBN features have on nursing practices and client outcomes. Specifically consider RBN features related to: education, skills, and contextual knowledge; personal nature and characteristics; and their informal networks and familiarity within the context. Also consider how each individual RBN might engage diplomatically with key players within each healthcare system.
  - c. general clientele features (and individual clients) have on breast nursing practices and client's outcomes. Specifically consider clientele features related to: disease and treatment characteristics, and health status; social, physical, and financial circumstances; and approach, personality, and preferences.
2. Support measures to enhance the reality and perception of the availability and accessibility of RBNs, women, and healthcare services/providers to one another.

These broad recommendations can be translated into concrete specific recommendations for relevant groups. Specifically, planners, managers, and RBNs should implement these findings on a practical level. Service planners, managers and employing organisations, and RBNs must consciously organise referral pathways, ensure the availability and accessibility of RBNs to clients and the healthcare team, organise services responsive to the needs of their clientele, and be transparent to clients and the healthcare team about the intended dose, delivery, and content of RBN services.

More specifically, the importance of clinical confidence and RBN experience in providing nursing care should not be underestimated. These appear to be especially critical in rural settings. Clinical confidence and RBN experience should be acknowledged as necessary for effective practice, as they can severely limit practice when appropriate confidence and relevant experience are not present.

Additionally nursing groups and educational institutions should heed the need for educational preparation for BNs. Educational institutions should consider how to incorporate diplomacy into curriculums for advanced nurses, what “diplomacy” is and how one might teach it. Also, what circumstances might benefit most from a “skilled diplomat”.

Researchers can aim to improve nursing practices and client outcomes through what is investigated and how findings are presented. Researchers should; develop and explore fatigue interventions for people with cancer including their implementation into real world practice; and consider nursing dose, delivery, and content when describing and/or assessing and presenting nursing interventions. Also, validity concerns raised here and elsewhere about respondents understanding of the SCNS should be directly assessed in future studies to ensure valid and reliable data collection tools are available.

More specifically, future research should improve understandings around educational preparation, skill level, and diplomacy (e.g. what it is and how it could

best be taught). The significance of the variability in nursing practice identified in this study would benefit from further study.

Furthermore, future research should assess the relevance and application of the conceptual framework of RBN practice in other settings. For example, the framework's usefulness should be assessed in other rural contexts as well as BN, rural nursing, and rural supportive care practices.

In conclusion, this pragmatic mixed methods study advanced knowledge of rural breast nurses' practice within real world contexts. A conceptual framework for breast nurses' practice in rural settings was developed based on the quantitative and qualitative findings, and building on a generic nursing conceptual intervention framework (Sidani & Braden, 1998). RBN practice was influenced by contexts and RBNs. Additionally, a comprehensive description of RBN practice was provided along with an assessment of client outcomes.

**Appendix 1 has been removed due to copyright or proprietary reasons**

**Appendix 1 has been published as:**

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## STATEMENT OF AUTHORSHIP

### SUBMISSION

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### CONTRIBUTIONS and proportionate authorship

<b>Melinda Minstrell</b>	86%
Lead researcher and author – ultimate responsibility for research	
Preparation and presentation of key themes	
Data collection, entry and analysis in SPSS	
<b>Tania Winzenberg</b>	6%
Advice on SPSS data set up and statistical analysis	
STATA data analysis (comparisons of proportions)	
Wording suggestions	
<b>Nicole Rankin</b>	4%
Recommendation of assessment tool (Supportive Care Needs Survey)	
Content knowledge insights and suggestions	
<b>Clarissa Hughes</b>	3%
Comments and suggestions on overall research direction	
Suggestions on readability and cohesion of submission	
<b>Judi Walker</b>	1%
Comments and suggestions on overall research direction	

## **Appendix 2      Supportive Care Needs Survey**



### **SUPPORTIVE CARE NEEDS SURVEY (SCNS)**

This survey was developed by: Cancer Education Research Program  
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**Appendix 2 has been removed due to copyright or proprietary reasons**

### **Appendix 3      Specific items relating to Supportive Care Needs Survey Domains**

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**DOMAIN: Psychological (22 items)**

---

Fears about losing your independence  
The confusion about why this has happened to you  
Feeling bored and/or useless  
Anxiety  
Feeling down or depressed  
Feelings of sadness  
Fears about the cancer spreading  
Fears about the cancer returning  
Fears about pain  
Anxiety about having any treatment  
Fears about physical disability or deterioration  
Accepting changes in your appearance  
Worry that the results of treatment are beyond your control  
Uncertainty about the future  
Learning to feel in control of your situation  
Making the most of your time  
Keeping a positive outlook  
Finding meaning in this experience  
Feelings about death and dying  
Concerns about the worries of those close to you  
Changes to usual routine and lifestyle  
Concerns about the ability of those close to you to cope with caring for you

---

**DOMAIN: Health System & Information (15 items)**

---

Hospital staff to convey a sense of hope to you and your family  
The opportunity to talk to someone who understands and has been through a similar experience  
To be given written information about the important aspects of your care  
To be given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home  
To be given explanations of those tests for which you would like explanations  
To be adequately informed about the benefits and side-effects of treatments before you choose to have them  
To be informed about your test results as soon as feasible  
To be informed about cancer which is under control or diminishing (that is, remission)  
To be informed about things you can do to help yourself get well  
To be informed about support groups in your area  
To have access to professional counselling (eg, psychologist, social worker,

counsellor, nurse specialist) if you/family/friends need it  
To be treated like a person, not just another case  
To be treated in a hospital or clinic that is as physically pleasant as possible  
To be given choices about when you go in for tests or treatment  
To have one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up

---

**DOMAIN: Physical & Daily Living (7 items)**

---

Pain  
Lack of energy/tiredness  
Nausea/Vomiting  
Feeling unwell  
Not sleeping well  
Work around the home  
Not being able to do the things you used to do

---

**DOMAIN: Patient Care & Support (8 items)**

---

Waiting a long time for clinic appointments  
Family or friends to be allowed with you in hospital whenever you want  
More fully protected rights for privacy when you're at the hospital  
More choice about which cancer specialist you see  
More choice about which hospital you attend  
Reassurance by medical staff that the way you feel is normal  
Hospital staff to attend promptly to your physical needs  
Hospital staff to acknowledge, and show sensitivity to, your feelings and emotional needs

---

**DOMAIN: Sexuality (3 items)**

---

Changes in sexual feelings  
Changes in sexual relationships  
To be given information about sexual relationships

---

**No specific factor loadings (4 items)**

---

Talking to other people about the cancer  
Changes in other people's attitudes and behaviour towards you  
Concerns about your financial situation  
Concerns about getting to and from the hospital

---

## **Appendix 4      Consultation Log Sample**

Patient code: \_ \_ \_ \_

SBN Code \_ S \_

Date \_ / \_ / \_

**SBN CONSULTATION LOG**

REFERRAL FROM: \_\_\_\_\_ (name)

WHEN: ☐ Diagnosis ☐ Pre Operative ☐ Post Surgery  
☐ 1 - 6 wks Post Operative ☐ 6 - 10 weeks Post Operative ☐ Other \_\_\_\_\_If Other INITIATED BY: ☐ Nurse ☐ PatientCONTACT TYPE: ☐ Face-face ☐ Phone ☐ Other \_\_\_\_\_

CONSULTATION TIME: \_\_\_\_\_ minutes

MARK THE TOP 3 AREAS OF DISCUSSION WITH AN ASTERICK " \* "

ACTION	YES	COMMENTS
<b>BASIC</b>		
• Introduced self & role		
• Met with partner and/or family		
• Provided with contact # and availability details		
• Discussed extent of desired involvement in decision making		
• Discussed "what happens next"		
<b>HEALTH SYSTEM &amp; INFO DOMAIN</b>		
• Assessed understanding of treatment goal		
• Assessed understanding of diagnosis		
• Assessed understanding of prognosis		
• Discussed implications of results and prognosis		
• Discussed treatment options		
• Discussed treatment plan and goal		
• Discussed possible complications and side effects from therapy		
• Discussed adjuvant therapy		
• Discussed breast reconstruction		
• Discussed roles and offered referral of other resource personel (eg physiotherapist, social worker, etc)		
• Discussed roles and offered referral to Breast Cancer Support Service & Cancer Connect		
• Discussed clinical trials		
<b>PHYSICAL &amp; DAILY LIVING DOMAIN</b>		
• Provided information on hospitalisation (eg. time, costs, and practical support on discharge)		
• Discussed prosthesis scheme		
• Discussed travel and accomodation scheme		
• Discussed wig & hat scheme		
• Discussed general financial assistance		
• Discussed managing side effects		
• Discussed complication prevention (eg wound and drain care)		
• Assessed and discussed need for home-help		
• Discussed possible future problems (eg lymphoedema)		

Patient code: \_ \_ \_ \_

SBN Code \_ S \_

Date \_ / \_ / \_

<b>PSYCHOLOGICAL DOMAIN</b>		
• Checked for major psychological problems		
• Discussed reactions to diagnosis / potentially threatening procedure / prognosis		
• Discussed expectations of treatment (surgery, radiotherapy, chemotherapy, etc)		
• Discussed level and extent of anxiety and depression		
• Assessed risk factors for psychological problems		
• Checked support networks		
• Assessed and discussed current support networks (eg family / social)		
• Discussed family issues and needs		
• Discussed past experience of family and friends with breast cancer		
• Discussed psychosocial impact of cancer and treatment		
• Discussed effects on self identity		
• Discussed cultural, religious & spiritual issues		
<b>SEXUALITY DOMAIN</b>		
• Discussed treatment impact on body image		
• Discussed effects of treatment on sexuality		
• Discussed intimacy and interpersonal relationships		
• Discussed menopause symptoms		

Intervention provided: *Tick all that apply for this consultation***Written resources:**

- |  |   |
|--|---|
| <input type="checkbox"/> personal reactions                        | <input type="checkbox"/> practical daily living |
| <input type="checkbox"/> health schemes (travel, prosthesis, etc.) | <input type="checkbox"/> sexuality              |
| <input type="checkbox"/> prof / volunteer support                  | <input type="checkbox"/> treatment plan         |
| <input type="checkbox"/> home-help                                 | <input type="checkbox"/> resource personel      |
| <input type="checkbox"/> community resources                       | <input type="checkbox"/> other _____            |
| <input type="checkbox"/> Treatment (surg, chem, radio, hormone)    |   |

**Referrals / Direction** *either written or verbal:*

(include names please)

- |   |   |
|---|---|
| <input type="checkbox"/> professional support _____ | <input type="checkbox"/> medical oncologist _____     |
| <input type="checkbox"/> volunteer support _____    | <input type="checkbox"/> radiation oncologist _____   |
| <input type="checkbox"/> physiotherapist _____      | <input type="checkbox"/> reconstruction surgeon _____ |
| <input type="checkbox"/> community nurse _____      | <input type="checkbox"/> other _____                  |
| <input type="checkbox"/> general practitioner _____ |   |

Day .....

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

SBN Code \_\_\_\_

SBN DAY LOG

Table 1: Time spent doing patient related duties

ACTIVITY	DESCRIPTION	Pt 1	Pt 2	Pt 3	Pt 4	Pt 5	Pt 6	Pt 7	Pt 8	TIME SPENT Hrs Min
	* ID									
Clinical duties (face-to-face)	Wound assessment, dressings, r/o drains and sutures, aspiration of seroma's, assessing lymphoedema									
Supportive (sitting in with Dr)	Sitting in with Dr whilst information given to pt & providing support, gauging pt's response etc									
Supportive Care (info & support)	Face-to-face contact, Providing information, discussing options. Supportive care (emotional, social, tangible, reassurance). Include support given to family.									
Face to face contact	Phone contact, Providing information, discussing options. Providing supportive care to patient and/or family									
Supportive care (info & support)	Updating patient's medical record notes, updating patient's file, data base entry									
Documentation										
Staff Hand-over (verbal)	Providing/receiving verbal hand over to/from other staff members - issues relating to patient's care									
Referrals/ Appointments (Pt-related phone calls)	Organising/receiving referrals to other health professionals and Breast Cancer Support Service. Include time taken to make patient related phone calls.									
TOTAL TIME										
	Patient contact (not captured elsewhere)	Informal contact with patients (ie chatting with prediagnosed patients in clinic waiting room)								
	Leading support groups	Leading or assisting with support groups run for women with breast cancer								
	Multidisciplinary meeting	Meeting with other health professionals involved in pt's treatment. Discussion of new pt's diagnosis, plan of treatment, follow up or discharge plan.								
		TOTAL TIME SPENT: PATIENT RELATED ACTIVITIES								

\* ID - Pt code or initials

Appendix 5 Day Log Sample

Day .....

Date \_ \_ / \_ \_ / \_ \_

SBN Code \_\_\_\_\_

Table 2: Time spent doing other duties.

**SBN DAY LOG**

ACTIVITY	DESCRIPTION	TIME
Administration	Preparing information packs, resource development, photocopying, responding to mail, phone calls & faxes, completing forms (eg prosthesis voucher) etc	
Education (teaching)	(i) Giving seminars, presentations, inservices. (ii) Acting as preceptor for nursing graduates. (iii) Acting as resource for other health professionals.	
Education (personal develop.)	Attending lectures, presentations, or inservices. Reading journals, articles or other literature which contributes to professional development	
Debriefing	Discussing and expressing feelings in relation to difficult patients and/or situations with other staff members (eg treating a young woman with advanced breast cancer).	
Staff meeting	Meetings with other health professionals to discuss administrative, house keeping type of issues	
Staff contact (other)	Other forms of staff contact not captured else where.	
Meetings	Include committees, working parties, health promotion meetings etc	
Travel	Work related travel (eg home visits, attending meetings, giving talks etc)	
Project related activities (evaluation project)	Liaising with investigator or staff in relation to specialist breast nurse evaluation project. Discussing project with eligible women, gaining consent from willing participants, completing logs.	
Other	Any other non-clinical activities not captured else where.	
<b>TOTAL TIME</b>		

Total hours worked today as a specialist breast nurse / breast care nurse: \_\_\_\_\_ hours

Was today representative of a typical day for you? Y / N





Appendix 6 Study Patient List Sample

SBN-HELD RESEARCH STUDY PATIENT LIST

SBN Code \_\_S\_\_

PURPOSE: This list is designed for SBNs to record the number of contacts with each patient including other consults (initiated by patient or SBN). The list will be forwarded to the investigators at the conclusion of the study, with the shaded portions excluded.

PATIENT			CONSULTATIONS							OTHER
Patient Name	Diagnosis date	Invited Participation	Patient Code	Diagnosis Consultation	Pre Op Consultation	Post Op Consultation	1 - 6 wks Post Op	6 - 10 wks Post Op	Patient Initiated	SBN Initiated
Mrs A. Patient	3/03/2003	X	NW 1							
Mrs J. Smith	5/03/2003		NW 2	X	X	X				
			S 1							
			S 2							
			S 3							
			S 4							
			S 5							
			S 6							
			S 7							
			S 8							
			S 9							
			S 10							
			S 11							
			S 12							
			S 13							
			S 14							
			S 15							
			S 16							
			S 17							
			S 18							
			S 19							
			S 20							
			S 21							
			S 22							
			S 23							

## Appendix 7      Semi-structured Interview Template

### INTERVIEW TEMPLATE *EXTENT OF ABILITY, DECISION-MAKING, MEDIATORS, & CONTEXT*

Learn from you, not to judge or evaluate you

Interested in BN role experiences in rural context – examples helpful, exclude names

Approx 1 hr... what time do you need to finish?

**Consent form & begin recording**

**Can you briefly explain how you came to work in the breast nursing role?**

Experiences which may have helped

**1. Will you organise these supportive care issues in order of your confidence (most-least), and talk through the order (why easy / hard & how handle)?**

**1. Are there any specific items you find particularly challenging? How do you deal with this?**

Energy levels and fears of recurrence

Exceptions to the rule

Unable to help under best circumstances

**2. How do you decide what to do with a patient (e.g. what sorts of things do you consider)?**

Care pathways / protocols (e.g. NBCC)? useful?

How determine issues for assistance

**2. How do you prioritise your work (needs, referral source, point in journey, liaising w/ others)?**

**3. Are there things which *help* you to provide the best breast nursing care possible? How?**

Personal, organisational, Infrastructure, and / or resources

**3. Are there things which *stop* you from providing the best breast nursing care possible (i.e. referral)? How?**

Personal, organisational, Infrastructure, and / or resources

How impact your outcomes / effects

Major recurrent causes of frustrations

**4. Is there anything specific about the regional community that affects what you do and / or how you do things?**

Is there anything I should have asked you, but didn't?

Please call or email if other things you've thought of that you'd want to include.

I will get back to you with the transcript for you to look over. I may have questions when I look over my notes, is it OK if I contact you again?

*Tell me more about \_\_\_\_\_*

*Can you give me an example?*

*Silence*

*Other's told me about that, but I haven't heard much about \_\_\_\_\_*



## Appendix 8 Training Materials for Breast Nurses

### BREAST NURSE STUDY OVERVIEW

- a) **Approved ethics application**
- b) **SBN information sheet & consent form**
- c) **Breast nurse activities**
  - Recruiting Patients – mail weekly (small envelope)
  - Study Patient list – mail at the end of the study  
*Include all eligible patients, even if they are not participating in study*
  - Day Log – one week per month (large envelope)
  - Consultation Log – mail monthly (large envelope)  
*Include all eligible patients, even if they are not participating in study*
  - Interviews – month 10 / 11

### ESTIMATED TIME REQUIREMENTS

RESEARCH TOOL	TIME REQUIRED	HOW OFTEN	BY WHOM
SBN Day Logs	5 minutes per day	1 wk / month for 12 months	Specialist breast nurse
SBN Consultation Logs	4 extra minutes	every consultation	Specialist breast nurse
Supportive Care Needs Surveys	15 – 20 minutes	twice	Patients with breast cancer
Obtaining consent from patients	3 minutes per patient	each breast cancer patient	Specialist breast nurse
SBN-held Research Study Patient List	5 minutes per week	ongoing	Specialist breast nurse
Telephone surveys - treatment team	20 minutes	once	Treatment team member
Telephone survey - SBN	45 minutes	once	Specialist breast nurse
Focus Groups with patients	1.5 hours	once	Focus group participant

### DIRECTIONS FOR BREAST NURSES

#### ONGOING

- **Recruiting eligible patients**
  - Invite patient participation with information sheet, if consenting have them fill in the consent form (the patient keeps the info sheet)
  - Mail consent forms weekly in small reply-paid envelopes
- **Record eligible patients and consultations on 'study patient list'**
  - Unshaded portion will be given to investigators at end of study
- **Complete consultation logs for eligible consultations**
  - Tick boxes and write comments
  - Record patient code in top right corner
  - keep a copy for your own records if you'd like
  - mail once per month in large orange A4 folders

#### MONTHLY

- **SBN Day Log**
  - complete every working day for one week every month (Melinda to send email reminders)
  - mail once per month in large orange A4 folders

#### ELIGIBILITY NOTES

- **eligible** = patient's consulting with a specialist breast nurse or breast care nurse for early breast cancer during the study period. Patients must be over 18 years of age and will be excluded if their English abilities would inhibit their completion of the Supportive Care Needs Survey.
- **ineligible** = under 18, advanced disease, non-english speaking
- **IMPORTANT NOTE:** An eligible patient may or may not have consented to participate with the survey. Either way, de-identified information is allowed to be collected regardless of consent (eg. Consultation Logs and Study Patient List)

## DIRECTIONS FOR INVESTIGATORS

### ORGANISATION

- Utilise "investigator records" as master document
- Mail out SCNS with cover letter and reply envelope
- Mail out reminder letter with a second SCNS and reply envelope
- SCNS must have SBN code and patient code written on them prior to mail out
- Reply paid envelopes must have "Attn: Melinda Minstrell" above the address
- Cover letter and reminder letter to be printed on plain white paper

### PROMPT / DAILY

- **Enter consent form information**
  - Collect from small reply-paid envelopes
  - Enter SBN code, name, address, and date of diagnosis
  - Give the patient a patient code (eg. 1)
- **Send SCNS**
  - Based on 1M date and 3M date
  - Write the SBN code and patient code on the SCNS (eg. N2 – 3)
  - Send reminder letters if dates have been reached without receipt
  - Send copy of consent form
- **Record received SCNS**
  - Put dash through reminder section so reminder is not accidentally sent

### ONGOING

- **Organise Consent forms**
  - Keep in alphabetical order by last name in locked cabinet
- **Enter data**
  - SCNS
  - SBN Consultation Logs
  - SBN Day Logs

## SBN Day Logs

**HOW OFTEN**      One week / month  
(use one log for every day worked as a breast nurse during the one wk)

**WHICH WEEKS**      Second week for every month

2003

July 7 – 13  
August 4 – 10  
September 8 – 14  
October 6 – 12  
November 3 – 9  
December 8 – 14

2004

January 12 – 18  
February 9 – 15  
March 8 – 14  
April 5 - 11  
May 10 - 16  
June 7 - 13

## Appendix 9 Analysis results guiding decision-making around missing and overlapping data

### Comparison of 'other consultations' initiation source and number within Study Patient Lists and Consultation Logs

	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
total number of 'other' consultations as per study patient lists	446	161	204	81
client-initiated 'other' consultations as per study patient lists	45% (200)	50% (80)	47% (96)	30% (24)
RBN-initiated 'other' consultations as per study patient lists	55% (246)	50% (81)	53% (108)	70% (57)
total number of 'other' consultations as per consult logs	252	74	142	36
client-initiated 'other' consults as per consult logs	43% (109)	31% (23)	55% (78)	22% (8)
RBN-initiated 'other' consults as per consult logs	44% (110)	43% (32)	37% (53)	69% (25)
other' consults with unknown initiation source as per consult logs	13% (33)	26% (19)	8% (11)	8% (3)

### Comparison of consultation timing data within Study Patient Lists and Consultation Logs

	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
Consultations within '5 in 12 model' (%) - consult logs (n =853)	70% (591)	75%	62%	79%
Consultations considered 'other' or additional - consult logs	30% (252)	25% (74)	38% (142)	21% (36)
Consultations within '5 in 12 model' (%) - study patient lists (n = 1039)	57% (593)	59% (236)	51% (215)	64% (142)
Consultations considered 'other' or additional - study patient lists	43% (446)	41% (161)	49% (204)	36% (81)

\* see methods chapter for discussion of why less consultation logs were completed, and patterns of non-response.

**Consultation delivery modes within Consultation Logs: comparisons of excluding and imputing missing data**

	Summarised RBN (n = 6)	Community RBN Site (n=3)	Public/Private Hospital RBN Site (n=1)	Private Hospital RBN Site (n=2)
KEY: % (n)				
Face-to-face consultations excluding missing data	65%	62%	70%	57%
Telephone consultations excluding missing data	35%	38%	30%	43%
Face-to-face consults where missing data imputed as face-to-face	70%	64%	75%	65%
Telephone consults where missing data imputed as face-to-face	30%	36%	25%	35%

*NOTE: imputing missing data (assumed were face-to-face) led to decreased telephone consults by 5, 2, 5, and 8% respectively*



## Appendix 10      Prevalence of High Unmet Needs for all Items at One Month and Three Months Post-Diagnosis

ITEM	TIME ONE	TIME TWO
<b>SEXUALITY DOMAIN (3 items)</b>		
changes in sexual feelings	5.4% (4)	8.6% (7)
changes in your sexual relationships	4.1% (3)	8.6% (7)
being given information about sexual relationships	2.7% (2)	4.9% (4)
<b>PSYCHOLOGICAL DOMAIN (22 items)</b>		
fears about losing your independence	13.5% (10)	9.9% (8)
making the most of your time	6.9% (5)	8.6% (7)
anxiety about having any treatment	29.7% (22)	25.6% (21)
fears about cancer spreading	35.1% (26)	22.0% (18)
fears about the cancer returning	31.5% (23)	22.0% (18)
concerns about the worries of those closest to you	39.7% (29)	20.7% (17)
anxiety	18.9% (14)	19.5% (16)
accepting changes in your appearance	10.8% (8)	19.5% (16)
uncertainty about the future	28.8% (21)	19.5% (16)
feelings of sadness	17.6% (13)	18.3% (15)
confusion about why this has happened to you	13.5% (10)	17.1% (14)
worry that the results of treatment are beyond your control	27.0% (20)	17.1% (14)
learning to feel in control of your situation	17.8% (13)	16.3% (13)
changes to your usual routine and lifestyle	25.7% (19)	16.3% (13)
keeping a positive outlook	13.5% (10)	15.9% (13)
feeling bored and/or useless	9.5% (7)	14.6% (12)
finding meaning in this experience	15.3% (11)	13.9% (11)
feelings about death and dying	19.2% (14)	13.6% (11)
feeling down or depressed	13.5% (10)	13.4% (11)
fears about pain	10.8% (8)	13.4% (11)
concerns about the ability of those close to you to cope with care for you	20.3% (15)	13.4% (11)
fears about physical disability or deterioration	9.6% (7)	12.3% (10)
<b>PHYSICAL &amp; DAILY LIVING (7 items)</b>		
lack of energy or tiredness	21.6% (16)	30.9% (25)
not sleeping well	14.9% (11)	26.3% (21)
not being able to do the things you used to do	19.4% (14)	24.4% (20)
work around the home	12.2% (9)	20.7% (17)
nausea and/or vomiting	4.1% (3)	19.5% (16)
feeling unwell a lot of the time	5.5% (4)	14.8% (12)
pain	13.5% (10)	13.3% (11)
<b>PATIENT CARE &amp; SUPPORT DOMAIN (8 items)</b>		
reassurance by medical staff that the way you feel is normal	5.5% (4)	8.5% (7)
hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	6.8% (5)	7.4% (6)
waiting a long time for clinic appointments	8.1% (6)	7.3% (6)
hospital staff attending promptly to your physical needs	2.7% (2)	3.7% (3)
more choice about which cancer specialists you see	4.2% (3)	2.5% (2)
family & friends being allowed with you in hospital whenever you want	2.7% (2)	2.4% (2)
more fully protected rights for privacy when you're at the hospital	1.4% (1)	2.4% (2)
more choice about which hospital you attend	2.7% (2)	1.2% (1)

<b>No Specific Domain Factor Loadings (4 items)</b>		
changes in other people's attitudes and behaviour towards you	9.9% (7)	9.8% (8)
concerns about getting to and from the hospital	8.1% (6)	7.3% (6)
talking to other people about the cancer	18.9% (14)	19.8% (16)
concerns about your financial situation	14.9% (11)	17.1% (14)
<b>HEALTH SYSTEM / INFORMATION DOMAIN (15 items)</b>		
being given written information about the important aspects of your care	13.5% (10)	9.9% (8)
being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	12.2% (9)	9.8% (8)
being informed about your test results as soon as feasible	20.3% (15)	9.8% (8)
being treated like a person not just another case	5.5% (4)	9.8% (8)
being adequately informed about the benefits and side-effects of treatments before you choose to have them	21.9% (16)	8.6% (7)
being informed about support groups in your area	11.0% (8)	8.6% (7)
having access to professional counselling (eg. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	11.0% (8)	8.5% (7)
being given choices about when to go in for tests or treatment	12.2% (9)	7.4% (6)
being treated in a hospital or clinic that is as physically pleasant as possible	9.5% (7)	7.3% (6)
hospital staff conveying a sense of hope to you and your family	6.8% (5)	6.3% (5)
opportunity to talk to someone who understands and has been through a similar experience	13.7% (10)	19.5% (16)
being informed about things you can do to help yourself get well	23.0% (17)	18.5% (15)
being informed about cancer which is under control or diminishing (that is, remission)	18.3% (13)	13.6% (11)
having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	18.1% (13)	12.2% (10)
being given explanations of those tests for which you would like explanations	17.6% (13)	11.0% (9)

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